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الجامعة الأردنيـــة
كلية الدراسات العليا

التاريـــخ: / /

نموذج رقم (١٦)
اقرار والتزام بالمعايير الأخلاقية والأمانة العلمية وقوانين الجامعة الأردنية وأنظمتها وتعليماتها لطلبة الدكتوراه

أنا الطالب: [handwritten name, illegible] الرقم الجامعي: (٩٠٧٠٠٥٦)
تخصص: تمريض الكليـــــة: التمريض

عنوان الاطروحة:
Jordanian Intensive care nurses perceptions of end of life care: helpful behaviors and obstacles

اعلن بأنني قد التزمت بقوانين الجامعة الأردنية وأنظمتها وتعليماتها وقراراتها السارية المفعول المتعلقة باعداد اطروحات الدكتوراه عندما قمت شخصيا" باعداد اطروحتي وذلك بما ينسجم مع الأمانة العلمية وكافة المعايير الأخلاقية المتعارف عليها في كتابة الأطروحات العلمية. كما أنني أعلن بأن اطروحتي هذه غير منقولة أو مستلة من أطاريح أو كتب أو أبحاث أو أي منشورات علمية تم نشرها أو تخزينها في أي وسيلة اعلامية، وتأسيسا" على ما تقدم فانني أتحمل المسؤولية بأنواعها كافة فيما لو تبين غير ذلك بما فيه حق مجلس العمداء في الجامعة الأردنية بالغاء قرار منحي الدرجة العلمية التي حصلت عليها وسحب شهادة التخرج مني بعد صدورها دون أن يكون لي أي حق في التظلم أو الاعتراض أو الطعن بأي صورة كانت في القرار الصادر عن مجلس العمداء بهذا الصدد.

توقيع الطالب:............ التاريخ: ٢٧ / ١٢ / ٢٠١١

JORDANIAN INTENSIVE CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE: HELPFUL BEHAVIORS AND OBSTACLES

By
Khaldoun Mohammad Abed-Alkhaliq Hamdan

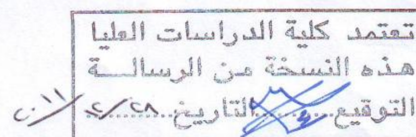
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This Dissertation was Submitted in Partial Fulfillment of the Requirements for the Doctor of Philosophy Degree in Nursing

Faculty of Graduate Studies
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December, 2011



COMMITTEE DECISION

This Thesis/Dissertation (Jordanian Intesive Care Nurses' Perceptions of End-of-Life Care: Helpful Behaviours and Obstacles) was Successfully Defended and Approved on 15/12/2011

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DEDICATION

This dissertation is dedicated to my son, the one who give me the spirit and power. To my supportive wife, who is always there. To my parents who guide me always to more success.

ACKNOWLEDGMENTS

I would like to thank my supervisor Dr. Jafar Alasad, for his support, patience and knowledge. Also my thanks to Dr Renea Beckstrand for her time and experience. I would like to thank the discussion committee (Dr. Muayad Al-Ahmad, Dr. Feryal Hayajneh, & Dr. Teresa O'Neill) for their time and efforts in reviewing my dissertation and for their fruitful feedback. Special thanks for every nurse participated in the study, and to every director facilitated the conduction of the study in the 23 chosen hospitals.

Endless thanks to my family for being always there.

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
BTICU	Burn and Trauma Intensive Care Unit
CCU	Coronary Care Unit
CPR	Cardiopulmonary Resuscitation
CVICU	Cardiovascular Intensive Care Unit
DNR	Do Not Resuscitate
ED	Emergency Department
EOL	End of life
EOLDM	End of life Decision Making
FATCOD	Frommelt Attitude Toward Care of the Dying
ICU	Intensive Care Unit
LST	Life Sustaining Treatment
MICU	Medical Intensive Care Unit
PIS	Perceived Intensity Score
PSS	Perceived Severity Score
RN	Registered Nurses
RT	Respiratory Therapists
SD	Standard Deviation
SICU	Surgical Intensive Care Unit
SPSS	Statistical Package for Social Science

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ABSTRACT

Background

The number of terminally ill patients who need end of life (EOL) care is increasing, especially in the intensive care units (ICU). Nurses usually encounter many obstacles in their delivery of EOL care. In Jordan, EOL care still in its infancy with absence of clear EOL care guidelines. Therefore, identifying the frequency and intensity of EOL care helpful behaviors and obstacles facing ICU nurses may help in modeling EOL care standards necessary for better quality of EOL care.

Purpose

The purpose of this study is to describe the perceptions of ICU nurses for the size and frequency of helpful behaviors and obstacles related to EOL care.

Method

A descriptive cross-sectional design was used in this study. The sample was collected using stratified random sampling design, based on the proportions of nurses within the regional clusters (north, middle, and south) and health sectors (private, governmental, and educational).

Results

Three hundred and twenty four respondents completed the questionnaire. The largest helpful behaviors perceived by nurses were: "Having family members accept that the patient is dying", "after the patient's death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit", and "providing a peaceful, dignified bedside scene for family members once the patient has

died". While the largest obstacles perceived by nurses were: "The nurse having to deal with angry family members", "the nurse having to deal with confused family members while still providing care for the patient", and "unit visiting hours that are too liberal".

Conclusion

Many of the highly rated obstacles were related to family issues and hospital environment. Collaboration of health care team members is also fundamental for successful delivery of EOL care.

CHAPTER 1

INTRODUCTION

Background

The moments surrounding death are the signal for an abrupt change in society's way of dealing with individual. Nurses are usually available at the beginning and at the end of life (EOL). Caring for patients at the EOL has dramatically changed over the past few decades. Trends have shifted from the abstract meaning of providing medical treatment toward facilitating "*good death"* (Ho, et al., 2005; Inghelbrecht, et al., 2009; Sprung et al., 2007*)*.

A *"good death"* is one that is pain free, dignified, and without resuscitation as requested by the patient (Jones and Willis, 2003). A good death should be natural, mature, expected, honorable, prepared, accepted, civilized, generative, rueful, and peaceable (Shneidman, 2007), which can be ensured through good palliation. Palliative care is an approach for improving the quality of life of patients and their families facing life threatening illness, through the prevention and treatment of physical, psychological, and spiritual problems (World Health Organization (WHO), 2002). It can be combined with curative medical treatment or alone as EOL care, to prevent and relieve suffering and to enhance patient comfort (Brener, 2007, pp. 3).

Providing a dignified and good death is crucial in facilitating EOL care (Gross, 2006) that should be a main component of nursing care. Nurses spend time with EOL patients more than any other health care provider (Jablonski and Wyatt, 2005; Popejoy, et

al., 2009). Nurses are responsible for wide range of nursing care activities, which require higher levels of critical thinking and interdisciplinary communication, coupled with intellectual and emotional efforts (Shuriquie, et al., 2007). Nurses' responsibilities are usually magnified in the intensive care unit (ICU) and expanded to the selection of the best and appropriate care for EOL patients and their families. Studies have emphasized the increasing number of patients in ICUs for whom curative care is unlikely to succeed and therapy is limited, with marked variation in life support practices (Carlet, et al., 2004). Therefore, the number of terminally ill patients who need EOL care is increasing especially in the ICUs. This expands the exposure to EOL care situations that usually surrounded by obstacles which need special attention to achieve optimal EOL care.

Research Problem

In Jordan, EOL care is still in its infancy with absence of clear EOL care guidelines. There is only one local institution that provides specialized palliative care. The King Hussein Cancer Center in Amman is a comprehensive cancer center which includes palliative care for inpatients, outpatients and patients at home (Stjernsward, et al., 2007). EOL patients are not always cancer patients, therefore there is a need to expand such care beyond the context of cancer care to include all areas of care provision.

Death can occur at any age, but more commonly occurs with old age. Aging is the process of growing old that usually combined with successive physical, psychological and social losses (Smith, 2001, pp. 399).

Jordan relatively has young population, in which 37.3% of the population are under 15 years, and only 3.2 % are 65 years and above (Department of Statistics (DOS), 2004a).

On the other hand, Jordanian health care system is progressing, which can be obviously seen by the increase of life expectancy from 68 years in 1998 to 73 years in 2008 (Ministry of Health (MOH), n.d.). Therefore, an increasing number of elderly patients are expected in the future which will require a more organized national EOL care strategy that is culturally and religiously sensitive. Hweidi and Al-Hassan (2005) suggested the need for identifying factors that affect Jordanian nurses' attitudes toward EOL care and care for older clients in Jordan. Jordanian studies addressing those recommendations and related EOL care issues are lacking.

Despite the vast consensus among health care providers on the importance of providing EOL care, there are many obstacles facing nurses in the delivery of EOL care worldwide (Carlet, et al., 2004). Obstacles could be related to communication process, decision making, withholding or withdrawal of life sustaining treatment, nurses' experience in EOL care, and nurses', patients' families, or institutional issues (Beckstrand and Kirchhoff, 2005; Carlet, et al.; Gross, 2006; Inghelbrecht, et al., 2009; Weigel, et al., 2007). The number of obstacles may negatively affect the quality and safety of care (Gurses, et al., 2008) and decrease satisfaction of nurses, patients, and families (Abualrub and Al-Zaru, 2008; Metnitz, et al., 2004).

Jordan is experiencing advances in technology, especially in ICUs. Professional nurses in those units are prepared to work with critically ill patients using sophisticated technology. They also have had an emphasis during their education on addressing patients' physiological needs (Omari, 2009). Those curative measures are not always helpful for patients at EOL who need more emphases on caring behaviors rather than curative ones in order to achieve the best quality of life for patients and their families. When caring is

central to the philosophy of ICU management from the beginning, then good EOL care becomes an intrinsic attribute of intensive care (Carlet, et al., 2004).

Significance of the Study

End of life care has long attracted the attention of many researchers worldwide. At the Jordan national level, the EOL care obstacles and helpful behaviors have not been explored or documented properly. The ICU is where EOL care is needed most, because most people die there. Therefore, identifying the frequency and intensity of EOL helpful behaviors and obstacles facing ICU nurses will help in gaining an understanding of nurses' perception of EOL care for patients and their families. Identifying the frequency and intensity of EOL obstacles will also help in modeling EOL care standards, serving as a cornerstone to establish EOL care guidelines in Jordanian ICUs, that is culturally sensitive and evidence-based. This study would serve as baseline data for health care policymakers in Jordan to inform existing care policies and procedures, and to develop EOL care standards and guidelines. Furthermore, the results of this study will help in bridging the gap between ICU nurses and EOL care recipients, which would improve the quality of nursing care in general by identifying EOL care obstacles and helpful behaviors, and optimizes the provision of EOL care.

The study may contribute to nursing curricula in Jordan by highlighting the importance of EOL care concepts. This study will shed more lights on issues related to EOL care which should motivate nursing educators to integrate the concept of EOL care in nursing curricula and prepare student nurses for possible obstacles that can be faced and how to utilize helpful behaviors to ensure better quality of care.

Purpose and Research Questions

The purpose of this study is to explore the perceptions of Jordanian intensive care nurses for the size and frequency of helpful behaviors and obstacles related to EOL care. More specifically, in order to achieve this main purpose the following research questions are used to guide the study:

1- Which helpful behaviors in EOL care are perceived by intensive care nurses as the largest?

2- Which helpful behaviors in EOL care are perceived by intensive care nurses as the most frequently occurring?

3- Which of the EOL care obstacles are perceived by intensive care nurses as the largest?

4- Which of the EOL care obstacles are perceived by intensive care nurses as the most frequently occurring?

5- Is there a difference in rating EOL helpful behavior in relation to nurses' characteristics (years of ICU experience, age, gender, number of patients received EOL care by nurses, type of facility, region)?

6- Is there a difference in rating EOL obstacles in relation to nurses' characteristics (years of ICU experience, age, gender, number of patients received EOL care by nurses, type of facility, region)?

Definitions

“End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.” (Palliative Care Australia (PCA), 2008, p.8). End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realized when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community – working together to meet the needs of people requiring care” (PCA, 2008, p.8).

“Euthanasia: Is killing on request and is defined as a doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request” (Materstvedt, et al., 2003, p.98).

“Family: A family is defined as those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends” (PCA, 2008, p.8).

“Palliation: Palliation in relation to end of life care is the relief of symptoms and suffering caused by cancer and other all eventually fatal conditions. Palliation helps a patient feel more comfortable and improves quality of life but does not cure the disease. Palliation of symptoms is a key goal of care for both end of life and palliative care (PCA, 2008, p.10).

“Palliative care: is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life” (PCA, 2008, p.11).

“Perception in humans (conceptual definition): Describes the process whereby sensory stimulation is translated into organized experience” (Lindsay and Norman, 1977).

Perception (operational definition): Is the experience of helpful behaviors and obstacles related to EOL as reported by Jordanian nurses and will be measured using the national survey of critical care nurses' perceptions of end-of-life care questionnaire**.**

"Physician-assisted suicide: Is defined as a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request" (Materstvedt, et al., 2003, p.98).

"Religion: A bond between humanity and great-than-human power, it includes: (a) a commitment of individuals to a supernatural power, (b) feeling of presence of such power who conceives them, and (c) carrying out ritualistic acts in respect of that power" (Hussain, 2011, p.188).

"Spirituality: A way of being and experiencing that comes about through awareness of a transcendent dimension and that is characterized by certain identifiable values in regard to self, others, nature, life, and whatever one considers to be the ultimate" (Hussain, 2011, p.188).

"Terminal condition: A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing." (PCA, 2008, p.14).

Conceptual Framework

"Peaceful End-of-Life theory" represents the theoretical background of this study. This is a middle range theory developed by Ruland and Moore in 1998.The theory was generated based on empirical evidence that focus explicitly on linkage between process and outcome, in addition to a thorough review of the literature addressing several components of the theory (Ruland and Moore, 1998).

The central focus in developing the theory was to specify the complex and holistic nature of care for EOL patients, to be reflected through nursing interventions that can be clearly described and observed which express the notion of caring. So the aim of the theory was not on the dying itself, but on contributing to peaceful and meaningful living in the period of life remaining (Ruland and Moore, 1998).

The standard of the peaceful EOL was composed of knowledge derived from many resources. The final standard of care consisted of 16 outcome criteria that were examined and reduced into five outcome indicators (see figure 1): (1) not being in pain, (2) the experience of comfort, (3) the experience of dignity and respect, (4) being of peace, and (5) closeness to significant others (Ruland and Moore, 1998).

Being pain free was defined as not having the experience of pain. The experience of being comfortable was described as relief of discomfort, the state of ease and peaceful contentment, and pleasurable life, while being treated with respect was defined as being respected and valued as a human being. Being at peace involves feeling of calmness, harmony, contentment and being free of anxiety, restlessness, worries and fear. Closeness to a loved one is the feeling of connectedness to another human being who cares (Ruland and Moore, 1998). Each of the five outcome indicators was linked to specific nursing interventions that contributed to the attainment of the desired outcome. Those interventions were described in measurable terms (Ruland and Moore, 1998). The questionnaire that was used in this study, “National Survey of Critical Care Nurses’ Perceptions of End of Life Care” (see Appendix C), contains the aspects of the adopted outcome indicators and all of their nursing interventions (Beckstrand, 2001).

The Peaceful End of Life Theory was used in this study to ensure the coverage of the important aspects in EOL care. The findings were matched with the theoretical concepts which help in modeling the theory to suite Jordanian culture or help in supporting the concepts within the theory. The permission was taken from the theory developer to use it in the study (please see Appendix D). Figure 1 provides a summary of the Peaceful End of Life Theory and illustrates the relationship among its different concepts.

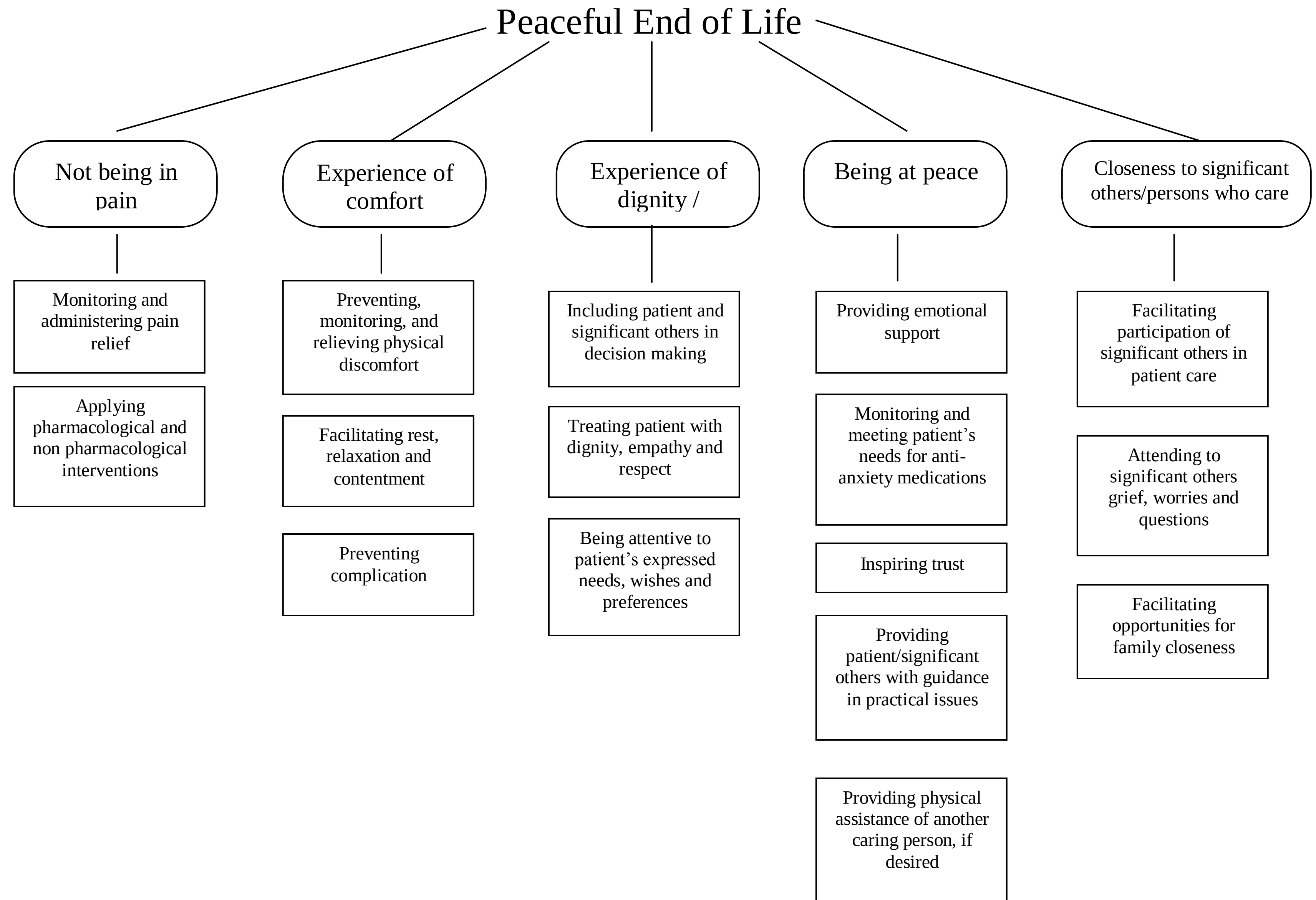


Figure 1. Relationships between the Concepts of the Peaceful End of Life Theory (Ruland and Moore, 1998)

Summery

End of life care is a growing field in Jordan. ICU nurses are usually the bridge between EOL patients, their families, health care professionals, and the many obstacles facing ICU nurses in their delivery of EOL care. The background about EOL care and good death were described in this chapter. The research problem was presented to capture EOL care situation in the Jordanian frame. Significance of the study, purpose and research questions, and definitions of the major concepts were presented. The Peaceful End of Life Theory was used as a theoretical background of the study.

CHAPTER 2

REVIEW OF LITERATURE

This chapter provides a review of the studies that have been conducted on issues related to EOL care. Five subheadings will organize the flow of data: 1) intensive care unit nurses and end of life care, 2) communication and decision making at end of life, 3) life sustaining treatment and peaceful death, 4) culture spirituality and religion at end of life, and 5) conclusion.

The search of the literature was conducted using CINAHL, PubMed, MIDLINE via EBESCO, and Science Direct data bases. The keywords used in the search were: EOL, EOL care, ICU, palliative care, nurses' perception, nurses' attitudes, helpful behaviors, obstacles, and spirituality.

Intensive Care Unit Nurses and End-of-Life Care

Death is a part of life, but it is neither simple nor natural if it is occurring in the ICU. Caring for dying patients and their families is thought to be most stressful and painful to the nurses who must constantly attend the patients (Beckstrand and Kirchhoff, 2005; McMillen, 2008; Ranse, et al., 2010). Moreover, performance obstacles increase the burden on nurses, which in turn negatively affect perceived quality and safety of care (Jablonski and Wyatt, 2005). Despite these performance obstacles, nurses are less likely to prefer to leave care of terminally ill patients to others. On the contrary, they are more likely to definitely agree that palliative or terminal care is a rewarding part of their work (Ranse, et al.; Vejlgaard and Addington-Hall, 2005).

Jordanian nurses reported moderately positive attitudes toward elderly patients. The nurses' years of experience factor significantly and positively correlates with the nurses' positive attitudes toward elderly patients (Hweidi and Al-Hassan, 2005). Similarly, Weigel, et al. (2007) found that higher levels of discomfort with dying patients have a higher correlation to nurses with less clinical experience. However, there were no significant differences in level of apprehension while still in nursing school found between nurses neither in relation to receiving training on caring for dying patients, nor to clinical experience. Likewise, Gross (2006), found that ICU nurses perceived lack of EOL care education as a small obstacle in their delivery of EOL care.

Most nurse practitioners (>74%) who attended the 2001 National Conference for Nurse Practitioners (n = 607) either agree or strongly agree that their work experience and education enabled them to discuss EOL care with patients and families. Also these nurses felt that having more EOL education and additional experience would enhance their communication abilities with patients and families regarding EOL care. Nurses who had a course or seminar on EOL care as part of continuing education, had a course on the patient self-determination act, or had personal experience with a terminal or life threatening illness had significantly greater level of comfort when initiating EOL care conversations (Tyree, et al., 2005).

Assessing Nursing Attitudes toward Death and Care for Dying Patients in a Comprehensive Cancer Center was the title of a study by Lange, et al. conducted in 2008. The aim of the study was to assess how nurses employed in a comprehensive cancer center feel about death and caring for dying patients and examine any relationships between their attitudes and demographic factors. A convenience sample of 335 inpatient and outpatient

oncology nurses was targeted to complete two part tool using a five point Likert scale, ranging from 1 = strongly agree to 5 = strongly disagree. The Death Attitude Profile scale is comprised of 32 items distributed in five subscales to determine respondents' feelings of (a) fear of death (negative thoughts and feelings about death), (b) death avoidance (avoidance of thoughts of death as much as possible), (c) neutral acceptance (death is neither welcomed not feared), (d) approach acceptance (death is viewed as a passageway to happy afterlife), and (e) escape acceptance (death is viewed as an escape from a painful existence). The other scale was the Frommelt Attitude Toward Care of the Dying (FATCOD), which is a 30-items tool measuring respondents' attitude toward caring for dying patients. Results of this study showed that the average score for all respondents on the FATCOD scale was 4.3, indicating strongly positive attitude toward caring for dying patients. In relation to age, results revealed that the older registered nurses (RNs) exhibited more positive attitudes toward caring for dying patients and were more likely to avoid talking about death than younger RNs. Older RNs viewed death with a neutral mindset, neither welcoming nor fearing death. They viewed death as an escape from a painful experience. In examining the relationships between nurses' attitudes and their experiences, it was found that RNs with more years of experience viewed death as an escape from a painful experience, which supports the finding that additional working experience leads to more positive feelings toward death. It had been noticed that that RNs without experience with the dying had more negative attitudes, reported more feelings of fear toward death, and avoided thoughts of death as much as possible.

In a study conducted in Korea by Jo, et al. (2009), to examine the effect of EOL care education by measuring nurses' experience with suffering, attitude toward death and

EOL care performance of Korean nurses in an RN- Bachelor of Science in Nursing program after completion of an EOL care education program. It has been found that there was no statistically significant correlation between the completion of an EOL care education program and nurse's degree of suffering, using pre-post test. Even though, the findings indicate that the suffering of an EOL patient influences a nurse's suffering experience and consequently informs the nurse's personal and cultural values as well.

In the same study, the EOL care education program contributed to the experimental group's positive attitude toward death, and consequently elevates the quality of a practicing nurse's EOL care performance, using the holistic approach to which the modern nursing apprise. It has seen that EOL care education improves EOL care performance, with respect to both the EOL patient and the patient's family, due to the recognition of symptoms and signs of death and dying, management of terminal symptoms, and skills of empathy with the patient and family (Jo et al., 2009).

Another study aimed to describe nurses rating of their skills and attitudes related to end of life care and their most recent experience with a patient's death, found that the mean of the summary score was significantly increased for nurses after providing educational seminar. Individually, 4 of the 10 communication items significantly improved. Total scores were significantly and positively correlated with years of experience. Forty four percent (44%) of nurses agreed or strongly agreed that family members interfered in the care of patients with terminal illnesses, nurses were also panic having to deal with emotional stress of family members (Zapka, et al., 2006).

Nurses with EOL experience and nurses who received training in palliative care had somewhat higher chance of agreeing on withholding or withdrawing life sustaining treatment. Also, nurses with higher education are more likely to be prepared to administer drugs in case of euthanasia and continues sleep sedation (Inghelbrecht, et al., 2009).

Communication and Decision Making at End-of-Life

Different opinions and perceptions of decisions at the EOL between consultants and nurses may lead to potential tension and conflict in agreeing action plan for the patient unless sensitivity held a part (Pugh, et al., 2009). Communication is considered a very important indicator of EOL care (Ho, et al. 2005). Nurses believe that having multiple physicians who differed in opinions about the direction of a patient's care is the biggest obstacle in providing EOL care, while having agreement among physicians about the direction of patient care was rated as the highest intensity supporting behavior (Beckstrand and Kirchhoff, 2005; Beckstrand, et al., 2009).

Despite the major role that nurses play in EOL care, and their agreement that it is primarily the task of nurses to deal with patients' reaction to death (Vejlgaard, et al. 2005); nurses are not always involved in the process of decision making. More than 22 % of EOL decisions were made without nurses' involvement and many of those decisions were made too late (Gurses, et al. 2008; Jox, et al., 2010; Yazigi, et al., 2005).

In a study conducted by De Veer, et al. (2008) to investigate the views of Dutch nurses on their role in discussing EOL decisions and their actual role in the decision making process and how this relates to the background characteristics of nurses, it has been found that nurses preferred to be involved by physician in EOL decisions. Most nurses

preferred to discuss such medical decisions in the final phase of life that might accelerate death like stopping life-prolonging treatments. A small number of Dutch nurses preferred to be involved in decisions of deliberately causing death, like physicians-assisted suicide or euthanasia. About three quarters of the nurses with palliative terminal patients have been involved in a medical EOL decisions making process in the last two years. Nurses who tend to talk about EOL decisions when giving care are twice as frequently engaged in decision-making processes. Nurses' involvement in the decision-making process is strongly and positively related to the number of palliative terminal patients cared by the nurse ($p \leq 0.001$, $F = 248.499$). In this study, about 62 % of the nurses are usually talk about issues related to EOL decisions most often with the patient and the family. Nurses more often tend to talk about these issues with the family (57%) than with the patient (45%) in the final phase of the care especially during the actual decision-making process.

Communication problems that restrict decision making are not limited to the health team only. Even families are suffering from those problems. Sometimes they are not involved in critical decisions related to their patients (Yazigi, et al. 2005). Physicians who are evasive and avoiding conversation with patients' family members are a major obstacle in EOL care (Beckstrand and Kirchhoff, 2005). Nurses believe that physician's behaviors, such as speaking to families after the patient's death and putting hope in tangible terms, can greatly facilitate EOL care (Gross, 2006).

In 2006, Nelson, et al. conducted a study entitled "End-of-Life care for the critically ill: A national intensive care unit survey", to elicit the views and experiences of ICU directors (nursing and physicians) across the United States, about current practices, barriers to optimal EOL care, and type, availability and perceived benefits of potential solutions to

improve this care. It has been found that the greatest magnitude of barriers (lowest mean scores) were related to patients/families category. About half of the directors reported that unrealistic (patient/family) expectations and inability of patients to participate in discussions were large or huge barriers.

In the clinician category, the significant barriers were related to communication by physicians, with one third of directors reporting insufficient training of physicians in communication about EOL issues and inadequate communication between the ICU physicians and patients/families about appropriate goals. Physicians lacking skills and time for adequate discussion were perceived as an obstacle to establish realistic treatment goals on which providers, patients, and families could agree (Nelson, et al., 2006).

Nursing directors reported greater concern than did physician directors about the role and skill of physicians, but both sets of directors believed that physicians stand in greater barriers than nurses. It has been noticed that ICU clinicians need training in the knowledge and skills to communicate with dying patients and their families, including the ability to discuss complex, distressing information clearly and sensitively; to approach decision making in the context of prognostic uncertainty; to elicit patient preferences; to assist patients, families, and colleagues in establishing realistic and appropriate treatment goals; and to resolve conflicts. Improved communication may reduce anxiety and distress and enhance satisfaction with care. Most of the respondents agreed about the helpfulness of the strategies suggested in the survey, like a family bereavement program, regular pastoral care visits, role modeling and close supervision of trainees by clinicians experienced in end-of-life care, and training of ICU clinicians in relevant communication skills. However,

the availability of almost all of these potentially helpful strategies for participating ICUs was limited (Nelson, et al., 2006)

The perceived needs of Jordanian families of hospitalized critically ill patients were identified in two different studies (Al-Hassan and Hweidi, 2004; Omari, 2009). Both studies found that Jordanian families of ICU patients are usually in need to receive information frequently, to feel that the hospital personnel care about the patient, to have the questions answered honestly and to know the patient progress and the expected outcome. Omari (2009) found that to be called at home about changes in the patient's condition was among the never met needs.

On the other hand, communication with patients' families can also be a significant obstacle in the delivery of EOL care, if it is not organized in the proper way (Beckstrand and Kirchhoff, 2005; Crump, et al., 2010; Gross, 2006; Zapka, et al., 2006). In the study of Beckstrand and Kirchhoff, it was found that patients' family members and friends, who continually called a nurse for an update on the patient's condition, rather than calling the designated contact person, was one of the highest intensity scoring obstacles. Also, nurses knowing a patient's poor prognosis before the patient's family knew the prognosis was rated as one of the highest frequency occurring obstacles. Nurses perceived that designation of a single family member as the contact person for all family members about information on the patient, is an important supportive behavior in providing EOL care.

Similarly, in a study conducted by Crump, et al. (2010), using the same questionnaire of Kirchhoff and Beckstrand (2000) to explore the obstacles (barriers) to, and supports for, EOL care in critical care units and to survey critical care nurses' perceived

knowledge needs for providing quality EOL care, it was noticeable that the obstacles regarding family and friends who continually call the nurse rather than designated family member for an update had the highest score. In this study, many of the items with the highest perceived intensity score were about family issues, followed by those pertained to physicians. In the same direction, the top supportive behavior was “having one family member be the designated contact person”, which correspond to the highest perceived obstacle.

Similar findings have been noticed for emergency nurses’ perception of size, frequency and magnitude of obstacles and supportive behaviors in EOL care, which revealed that 4 of the 7 highest ranked obstacles were related to issues regarding family members. They were: family members not understanding what “life saving measures” really means; the nurse having to deal with distraught family members; family members calling the nurse regarding patient status; and the nurse having to deal with angry family members. The 3 highest scoring obstacles overall were: the emergency department (ED) nurse having too high work load to allow adequate time to care for dying patients and their families, poor design of emergency departments not allowing for privacy of dying patients or grieving family members, and family members not understanding what “life-saving measures” really mean. Parallel to the obstacles, the 3 highest scoring supportive behavior were: allowing family members adequate time to be alone with the patient after he or she had died, having good communication between the physician and RN who are caring for the dying patient, and providing a peaceful, dignified bedside scene for family members once the patient has died (Beckstrand, et al., 2008).

Another study focused on the oncology nurses' perceptions of obstacles and supportive behaviors at the EOL by Beckstrand et al. (2009) found that eight of the top 10 obstacles related directly to family attitudes and behaviors. The highest rated obstacle to providing EOL care was "nurses having to deal with angry family members" followed closely by "families not accepting the patient's poor prognosis." Two similar top 10 obstacles were the fourth-ranked item, "dealing with anxious family members", and the sixth-ranked item, "the family being overly optimistic about patients' poor prognosis." In this study, oncology nurses identified "having family members accept that patients are dying" as the third-most supportive behavior, while the last top 10 helpful behaviors involved families, including "teaching family members how to act around dying patients" and "having one family member as a designated contact person for other family members regarding patient information."

Ball et al. (2010), collected data from 419 clinicians to better understand EOL processes after major injury by comparing clinicians viewpoints from various countries and cultures. About 49% of clinicians were from the United States, 19% from Canada, 11% from South Africa, 9% from Europe, 8% from Asia, and 4% from Australasia. Findings of the study indicated that most clinicians thought that EOL decision making varied significantly across countries and cultures, despite that, few respondents had formal medical futility laws or guidelines instituted by local governmental bodies to direct their practices. Except for Asia, most clinicians believed their individual faith or religion did not influence the EOL decisions provided in their practice. Most clinicians felt that their opinions and practices regarding EOL decisions and beliefs had changed with experience, and those opinions were in consistent agreement with institutional colleagues. For

resources availability, there was large variability in the number of institutions that offered ethical consultation services. The majority of respondents in both Asia and South Africa believed that resource limitations influenced their EOL decisions for severely injured patients. In relation to traumatic brain injuries; most clinicians, regardless of the region, responded that patient age was a significant factor in EOL decisions, with patient's age of 65 years as a noticeable threshold. Family presence and their ability to provide long term care for EOL patients, has a variable effect on the clinicians decision according to the region ranging from 16 to 100 %. Clinicians in Asia would consider withdrawal of treatment in 50% of patients, with complete paraplegia and intact diaphragm function.

The family is an integral part of treatment decision-making. In a study conducted in China by Wang, et al. (2004), 60 clinicians participated in the survey, including nurses (37%), residents (10%), fellows (37%), and attending physicians (15%). This study surveyed clinicians perspectives on EOL care in China regarding service availability, competence in pain and symptom management, patient and clinicians communication about terminal illnesses, and factors influencing a shift of treatment goals to palliative care. Respondents in this study gave greater weight to families' preferences than patients' preferences to disease disclosure and goal setting for treatment. So, patient's involvement in EOL decision making is rare, and few respondents felt that physicians and patients make decisions together. Also, the findings indicated the complexity of communicating truth to dying patients regardless of the degree of disclosure. A majority of the respondents would not inform a member of their own family if that person had a terminal disease, although most of them would like to be informed if they themselves had a terminal condition. Family pressure and concerns about depressing the patient were given as reasons for this

disclosure. EOL care was challenged by several barriers in the Chinese culture. Unrealistic expectations from the patient or family were identified as the most significant barrier, followed by patient or family denial of the terminal nature of the patient's illness. Other barriers included family conflicts and regulations regarding analgesics. Surprisingly, fifty three percent reported using placebos in controlling cancer related pain, 35% of them said that they were used placebos to reduce the risk of addiction. Participants reported having saline or vitamin C as placebos to treat pain in their practice, even most respondents (75%) reported the availability of pain services in their hospital.

Baggs, et al. (2007) conducted a study to describe the end of life decision making (EOLDM) cultures in four adult ICUs using prospective ethnographic design. Units studied were 17-bed medical ICU (MICU), a 20-bed surgical ICU (SICU), a 15-bed burn and trauma ICU (BTICU) and a 14-bed cardiovascular ICU. Results revealed that most patients were unable to participate fully in EOLDM because of lack of advanced directives, severity of illness, and use of technology in care.

Both similarities and differences in EOLDM among the four ICUs were influenced by formal and informal rules, by unit structure, by participants' roles and relationships, and by unit processes reflective of the culture. Differences in interpretation of formal and informal values had the potential to generate conflict between nurses and physicians, complicating EOLDM. Physicians were important shapers of the unit's culture, by their power over the use of technology and prescribing care modalities. The culture of MICU provides more time for the physician to spend with the family in comparison with SICU. EOLDM was usually delayed by physician until options are limited (Baggs, et al., 2007).

Life Sustaining Treatment and Peaceful Death

In critically ill patient, more interventions do not necessarily improve the outcome. On the contrary, it may increase patients' and family's suffering (Carlet, et al. 2004; Metnitz, et al. 2004). Futility of care because of a terminal illness as well as poor quality of life are the most important factors supporting the decision of withholding and withdrawal of life sustaining treatment (Yazigi, et al. 2005). Physicians, nurses, patients and families rank their preferences for quality of life higher than their preferences for value of life. Physicians and nurses want fewer applications of cardiopulmonary resuscitation (CPR) and mechanical ventilation than they did in ICU admission, and wanted fewer treatments if they had permanent unconsciousness or sever dementia (Sprung, et al., 2007).

Rocker, et al. (2005) conducted a study to understand and compare the perspectives of RNs and respiratory therapists (RT) who were involved in the care of patients who had life support withdrawn in the ICU. The majority of RNs and RTs were very comfortable with decisions about whether to withhold CPR and with decisions to withdraw life support. Most RNs and RTs were very comfortable with the timing of the decisions about CPR and life support withdrawal. Issues related to the availability of the physician, the peacefulness of the dying process and the amount of privacy were significantly less favorably rated by the RTs than the RNs.

The open ended questions of this study help to uncover important issues related to the subject. Nurses indicated that social attitudes and availability of medical technology may influence life sustaining treatment decisions which can be problematic for the elderly. So team approach to the decision-making process to withdraw treatment should be targeted,

which raise the need to standardize the withdrawal process, to have clear orders and to improve the timing of withdrawal process (Rocker, et al., 2005).

Many nurses agree or strongly agree that caring for patients who are dying is depressing (Zapka, et al., 2006). RNs experience more moral distress than physicians. The most distressing situations for both groups involved caregivers feeling pressured to continue aggressive treatment in situations where they did not think such treatment warranted. RNs with higher moral distress scores (as measured by Corley's Moral Distress scale) were more likely to have left or considered leaving a position than RNs with lower moral distress scores. These findings together with the significant relationship between moral distress and satisfaction indicate that the experience of moral distress may be a powerful factor in RN turnover (Hamric and Blackhall, 2007).

In clinical practice, nurses are constantly faced with providing futile aggressive treatment for patients at EOL (Gross, 2006; Yazigi, et al., 2005). Patients may still receive vasopressors, dialysis, and mechanical ventilation even they are diagnosed as 'do not resuscitate' (DNR) patients. The primary physicians or consultants are more likely to initiate discussion to withdraw or limit care, followed by ICU physicians, families, and nurses respectively (Salahuddin, et al., 2008).

Consultants are less likely to agree to withdraw treatment, stop hydration and to be in agreement to the practice of physician assisted suicide than nurses (Pugh, et al. 2009). Some physicians do not withdraw or withhold treatment because of personal philosophy that obligates them to sustain life at all costs, family's reaction to suggestions about withdrawal of life sustaining treatment or because it is not permissible by physicians'

religion (Salahuddin, et al., 2008). Most nurses believed that physicians should comply with patients request to withhold or withdraw a life sustaining treatment (Inghelbrecht, et al., 2009).

In a study conducted in 10 intensive care units of the Munich University Hospital in Germany, to investigate the practices and perspectives of German intensive care nurses and physicians on limiting Life Sustaining Treatment (LST), 197 participants were included in the study. From them, 149 were nurses and 48 were physicians, including attending physicians, residents and interns. Results showed that ninety one percent of all respondents reported a frequency of at least once a month confronting with the question of limiting LST for patients on the ICU. This implies that every 10^{th} patient poses the need to decide on limiting LST. The most LST mentioned by respondents were CPR while almost no respondents reported limiting artificial hydration. It seems that withholding emergency interventions like CPR easier than withdrawing ongoing LST. In the study, it has been shown that many German physicians erroneously think that withdrawing artificial ventilation by “pulling the plug” would amount to the illegal “active euthanasia”. This thinking led to rarely limiting mechanical ventilation in the studied ICUs. On the other hand, German law is clear on the legality of withholding and withdrawing LST; if the treatment is medically not indicated or contrary to patient will. Even though, 10% to 36% of respondents reported fear of legal consequences (Jox, et al., 2010).

The data on personal uncertainty correlated significantly with the respondents’ views about the insufficiency of training and the fear of legal consequences. This was reflected by the respondents’ statements of the strong need for information concerning medical, legal, and ethical aspects of EOL decision making. Less than a third of nurses

were satisfied with the decisions about LST compared with two thirds of physicians. Also, the nurses' satisfaction regarding the communication that precedes the decisions, were down to 16%. High correlation was found between satisfaction with the process of communication and with the decisions as the outcome of communication. The process of decision making was perceived by senior physicians as a cooperative one, shared by all team members, while nurses and junior physicians perceived the decision making process as an individual one made by the senior physicians (Jox, et al., 2010).

Almost half of the nurses reported that ICU physicians withhold information about diagnosis or prognosis from their patients occasionally or frequently. Most of these nurses reported frustration with the way physicians communicated with them about EOL care and were not satisfied with the patient-physician communication (Hamric and Blackhall, 2007).

Realistic information might help the families in making sound decisions as what to do next (Al-Hassan and Hweidi, 2004). Nurses cite not knowing the patient and family wishes concerning the continuation of life saving treatments as a medium obstacle (Gross, 2006), while cite patients' family members not understanding what the term life saving measures really meant as a large obstacle (Beckstrand and Kirchhoff, 2005).

In a study conducted in Israel by Natan, et al. (2010), which aimed to compare the importance attributed to different EOL needs by terminally ill older adult patients in long-term care facilities, their families, and care providers (physicians and nurses); five main needs stated as most significant by all research participant. Needs in descending order are: absence of pain, maintaining dignity, attentive staff, feeling comfortable with the nurse, and prevention of respiratory difficulties. Over 60% of the patients were not interested in using

all means to prolong their lives, including artificial feeding and respiration, when there was no potential cure. Of all patients, 86% would want to know the truth about their condition.

Family members and patients attribute more significance than medical and nursing staff to updating patients and families regarding patient medical condition. Elderly patients attribute more significance than physicians and nurses to the needs of remaining conscious, discussing fears, telling the truth, and ability to help others. They also attribute more significance than physicians to the need to include them in determining the care policy (Natan, et al. 2010).

Almost 50% of nurses disagreed that health care professionals provide patients and families with adequate information about EOL care choices. About 89% of the nurses either agree or strongly agree that EOL care discussions facilitate provider-patient/family agreement on treatment choices (Tyree, et al., 2005). It has been found that family members must begin to grieve to make the decisions that must be made. Grieving cannot begin until they hear about the patient’s condition and the options in clear, understandable terms without conflicting reports (Popejoy, et al., 2009).

In caring of EOL patients, efforts should be directed toward maintaining peaceful death. More than 90% of nurses agree that a terminally ill patient should receive drugs to relief pain and suffering (Inghelbrecht, et al. 2009). In a study conducted in Pakistan, more than 90% of ICU clinicians were using sedation and analgesics for EOL patients (Salahuddin, et al. 2008). Differently, a Lebanese study revealed that more than 60% of terminally ill patients did not receive any sedatives or analgesia (Yazigi, et al. 2005). More than 60% of nurses either disagree or strongly disagree that terminally ill patients have

adequate pain control (Tyree, et al., 2005). Patients having pain that is difficult to control or alleviate ranked as one of the 10 highest-rated obstacles perceived by oncology nurses (Beckstrand, et al., 2009). EOL care should also include patient's family. Family members need to be with their ill relatives to maintain the natural bond among them (Al-Hassan and Hweidi, 2004). Even after death, allowing patient's family members adequate time alone with the patient and providing a peaceful dignified bed side scene are considered important supportive behaviors for caring of patients at EOL (Beckstrand and Kirchhoff, 2005).

Similarly, the highest supportive items perceived by nurses in relation to intensity and frequency, in Crump, et al. (2010) study, were providing a peaceful dignified bed side scene after death, having physicians agree about the direction of care should go, allowing family members time to be alone with patient after death, and teaching family members how to act around dying patient. Also having the unit designed for patients to grieve in private and having physicians meet with the family after death were among the very supporting items but occurring infrequently.

Qualitative research also played a major role in exploring the hidden themes beyond EOL care. During the searching process, many studies have been found to help in better understanding of nurses' perception, feelings, and experiences in issues related to EOL care.

In Australia, a convenience sample of five intensive care nurses in a 14-bed intensive care unit at a tertiary teaching hospital were interviewed to explore the EOL care beliefs and practices of intensive care nurses. In this descriptive exploratory study, three categories were emerged. The first category was "beliefs about EOL care", in which

participants value their participation in providing EOL care for patients and their families, and used terms like “honor” and “privilege” to describe their feelings (Ranse, et al., 2010).

The second category was “EOL care in the intensive care context” which indicates three sub-categories. a) Emotional intensity, in which caring for EOL patients with terminal illnesses on a daily bases increase the grief and human suffering of ICU-RN, even they were expected (as ICU-RN) to cope with death and dying. This implies the need for emotional support which were existed extremely but not accessed. b) Organizational support, which was perceived by participants as an important need for EOL care. In this study, participants did not identify any specific policies or protocols that were available to guide EOL care. c) Uncertainty and ambiguity, that was related to the prognosis and EOL decision making. This ambiguity and uncertainty continue even after decisions had been made to withdraw treatment (Ranse, et al., 2010).

The third category was “facilitating EOL care”. Under this category, three subcategories were determined. a) Provide comfort care, participants believe that EOL care goes beyond removal of treatment only, it may include providing nursing interventions to ensure comfort care, like bathing, hair care, mouth care spiritual care and the administration of analgesics and sedatives. b) Modifying the environment, by providing single room to the patient and private relative room to the family which provide more privacy and space, and allow more visitors at the bed side. Also, the private room will help in decreasing the exposure of other patients and families to the dying scene. Modifying the environment may include removing clinical equipment, playing music, putting up photographs, and dimming lights which convert the environment into a homely one. c) Facilitating the family’s experience, through exploring what is happening to the patient and his/her family by

answering questions and providing information. Nurses can help in creating memories for the patient's family using simple actions like taking the patient's hand print, and keeping identity band with the family (Ranse, et al., 2010).

Another study conducted in north England by McMillen in 2008, used a purposive sample of eight ICU-RNs using semi-structured interviews, to explore the experience of ICU-RNs caring for patients who had their treatment withdrawn and to answer the following questions: what role do nurses play and how does this affect them? Analysis of the collected data revealed two major themes answering the research questions. Under each theme, several subthemes were identified. Under the first theme "the nurse's role" five subthemes were emerged: a) experience counts, which implies the importance of nursing experience in determining the role of nurses in EOL decision making and how much consideration is given to nurse' views. Senior nurses were recognized by the consultants and they seemed to listen to them, while junior nurses were almost fearful to speak up around consultants whom viewed as powerful people who by nature of their position have lots of experiences. b) Not really a nurses' decision. Nurses believe that they spend most of their time with patients and families, providing care and information, so nurses should have an important and significant input into the decision making process, but all participants felt that the decision to withdraw treatment was not theirs. c) Planting the seed. This nurses' role refers to that nurses are in position to think about the appropriateness of time to withdraw treatment on a patient before medical staff, then they will starting to hint to the medical staff that maybe it's the time to think about this decision. d) Supporting the family. Nurses are the ones who always available beside the family, and their responsibility to find out the families' views, concerns and wishes, and to prepare them for bad news. e) Being a

patient advocate, this implies the nurses' duty in protecting the patient safely to ensure the decision is a sound one.

The second major theme was "perceptions of withdrawal of treatment", which consist of two sub-themes: a) getting the timing right. For the family, it is important to feel the appropriateness of decision timing. If it is premature, they may feel as they accelerated patient's death, but if delayed it appears undignified. b) Emotional labor. Nurses are usually involved emotionally with their long-staying patients, and get upset when withdrawing treatment like turning off entropic drugs and decreasing ventilator support. This feeling is usually magnified if they are junior or/and their patients were young. Training junior nurses and providing support from senior ones play an important role in decreasing their emotional labor (McMillen, 2008).

In a similar qualitative study conducted in the United States by Calvin, et al. in 2009, 19 nurses were interviewed. The purpose of the study was to better understand cardiovascular intensive care unit (CVICU) nurses' perceptions of their role and responsibilities in the decision making process about EOL care and the change of its intensity for patients within the CVICU settings. In this study, four themes were identified:

1- Exhausting medical treatment. The patient role in the CVICU is to help patients to recover post-cardiovascular surgery using all available life-saving technologies. But when the hope of recovery is minimal, indicating the phase of EOL, nurses shift gear toward personal faith and spirituality to extend nursing care.

2- Promoting family presence. The nature of the CVICU provides limited privacy and visiting hours, which restrict family presence. Even though, nurses believe in the

importance of family gathering and its presence, which help in preparing families for the process of letting go, and enhance their acceptance of the patient death.

3- Acknowledging physician authority. Nurses in the current study are usually stand handicapped in front of physicians who are reluctant to discuss with family members the options of stopping medical and surgical treatments, fearing from physicians' reprimand. Physicians do not perceive that the patient condition is irreversible and medical treatment have been exhausted. Nurses acknowledge physicians authority in EOL decision making, his right as initiator of the discussion, and as a final decision maker.

4- Walking a fine line. Nurses are usually placed in moral struggling situations when patients are at the EOL. They perceive their primary role in clarifying patient's values and treatment wishes, while on the other hand, trying to avoid physician reprimand in such discussion. So nurses were held back during interviews or just kept silent, which put more strains on nurses' ability to provide comprehensive care (Calvin, et al., 2009).

Nurses working in acute medical wards also share some common perceptions in this subject. In a study conducted in Canada to develop an understanding of the process nurses undertake in providing quality end-of-life care and to develop an emerging theory grounded in the reality of the participants that captured their experiences in providing such care on an acute adult medical unit, one comprehensive theme was emerged "creating heaven for safe passage". Under this theme four sub-processes were identified. "Facilitating and maintaining a lane change" was the first one. It focuses on the recognition of the health care

team, patients, and their families that death is near, and to shift their thinking from curative medical treatment toward comfort care. Changing lanes is usually facilitated when the patients and their families have clear understanding of the disease process and its outcomes, and when they are active participants in the decision making process. The positive consequences of successful lane change include nurse's ability to establish a care plan that reflects the values and needs of the patients and their families, while negative consequences may include nurse's frustration and moral disturbance in providing active treatment for patients who need palliative care (Thompson, et al., 2006).

The second sub-process was "getting what's needed", which refers to the approaches that nurses utilize to meet the patient's physical needs through appropriate care plans. Physicians' lack of palliative care education and experience in care of the dying was a major barrier for nurses to be able to "get what's needed". The third sub-process was "being there", as a physical presence and an emotional support to family members of dying patients. This aspect was influenced by nurses being comfortable with themselves, family's acknowledgment that cure of the patient's illness was not possible, and the care context of the acute care medical unit. The last sub-process was "manipulating the care environment". Nurses believe that the physical surrounding environment affect the quality of care provided for the patient. This environment may include privacy through private rooms, relaxation measures, and proper decoration of the rooms (Thompson, et al., 2006).

Relatives' experiences were the main focus of a study conducted in the northwest of England by Lloyd-Williams, et al. (2009). The authors of the study interviewed the next of kin of 29 patients, distributed in twenty ICUs, to explore the EOL care experiences of brain dead intensive care patients. Analysis of the data identified four main issues. "Care of the

patient and relatives" was the main issue. Relatives were satisfied with the care provided for their patients and for them. Some families noticed that the workload on the unit restrain nurses thinking in providing physical care with little attention to the emotional needs.

The second issue of the findings was concerned with the "facilities". Relatives perceived the layout and facilities of the ICU were very poor. They did not feel any privacy with their loved one in the period of time preceding the machine being switched off. Also relatives were actually aware that their own distress would upset others, which made the last moments of saying goodbye very difficult. "Communication about death" was the third issue. Relatives did not understand several issues when their patients had died. Staff in the ICU did not recognize the suddenness and intensity of the event as perceived by relatives. Also staff did not communicate sensitively with the relatives. The last issue was "bereavement". Relatives felt their need to contact the heath team that had cared for their loved one, but found it difficult to initiate this contact themselves (Lloyd-Williams, et al., 2009).

In a qualitative study conducted in Mid-western community university hospital in the United States by Popejoy, et al. (2009), to elucidate the view points of ICU nurses about caring for critically ill and dying patients in the ICU; five major themes were identified:

1- Helping the patient through. This theme involved helping to support patients and their families. Nurses saw themselves as mediators between the patient, family, physician, and hospital.

2- Telling bad news. This involved balancing the nurses' individual beliefs with the beliefs of physician and the hospital organizational structures. Nurses strongly

believed that once families accept a patient's potential death, the grieving process begins.

3- Grieving as a process. Nurses believes that truth telling and support as a way to encourage patients and their families to begin to grieve their changing life state and move toward decision making.

4- Family as the patient. Nurses found satisfaction in helping families move toward acceptance of the patient's situation and probable death, and to take decisions that had to be made.

5- The dying patient's effect on the nurse. Nurses usually grieving for the loss of their patients and the emotional pain that the family is experiencing. Also, the difficulty of communication with highly stressed people in stressful circumstances affects all members of the health care team.

Quality indicators for EOL care in the ICUs entitled the study of Clarke, et al. (2003). Fifteen nurse-physician teams from 15 ICUs in the United States were recruited in the study. In depth literature review and domains extraction resulted in seven EOL care domains for use in the ICU. Those domains were: patient and family centered decision making, communication within the team and with patients and families, continuity of care, emotional and practical support for patients and families, symptom management and comfort care, spiritual support for patients and families, and emotional and organizational support for ICU clinicians.

Culture, Spirituality, and Religion at End-of-Life

This section was added as complementary to the literature review to clarify the effect of culture, spirituality, and religion on EOL care and related decisions. Brief description of certain EOL issues related to Christianity and Islam is presented to shed light on the importance of religion and spirituality at the EOL.

Prior to the discussion of spirituality, it is important to distinguish between spirituality and religion. Religion is defined as specific practices and beliefs that may be associated with an organized group. It is the vehicle that enables expressions of spirituality. Spirituality is defined as a unique experience that is a person's sense of people and purpose or expression of a great meaning and context (Kruse, et al., 2007).

Daaleman, et al., (2008) conducted a study in long term care facilities to describe the sources of spiritual support, the structure and processes of spiritual care, and to examine the relationship between these components and family rating of overall care. The sample consisted of 248 decedents' family members from a stratified sample of 100 residential care, assisted living facilities, and nursing homes. Results of this study revealed that (87%) of patients received support or care for their spiritual needs from multiple sources including clergy or chaplains (85%), family and friends (62%), facility staff (37%) and others (17%). It has been noticed that patients younger than 85 years and patients who are cognitively intact, were more likely to receive spiritual support from family and friends than patients who are older than 85 years or cognitively impaired. The overall care was rated higher by family members whose patients received component of spiritual support and care in the last

month of life. Patients who received spiritual support from facility staff rated care higher than those who did not (Daaleman, et al., 2008).

In a study conducted by Kruse, et al. (2007), a convenience sample of 60 adult patients was surveyed to examine relationships between spirituality and coping at EOL. Three measures were used: spirituality Well-Being Scale; Serenity Scale which describes experiences, thoughts and feelings related to serenity; and Cognitive Coping Scale. The Findings revealed high significant positive correlation among spiritual well-being, peacefulness, comfort and serenity. Also, significant positive correlations were found between spiritual well-being and importance of religion and cognitive coping. Cognitive coping was also correlated with faith and religion. So if we know that spirituality is a significant factor in creating a peaceful EOL and death, health care providers who work with EOL patients must address the spiritual needs of the dying and institute specific interventions to promote a peaceful death experience (Kruse, et al., 2007).

Nursing interventions to support spiritual health may include arranging visits with religious personnel, showing kindness, spending time listening to patients (presence), showing respect of patients needs, supporting friendships, supporting need for forgiveness, play music and facilitating time with nature (Wallace and O'Shea 2007).

On the other hand, the health care providers' beliefs play an important role in EOL care and decision making. In a study conducted by Pugh, et al. (2009), 119 consultants, 36 nurse key workers, and 44 specialist registrars were explored for their belief system and their attitudes to decisions which commonly must be taken when caring for individuals who are dying. The finding revealed that consultants were 10 times more likely not to believe in

an afterlife than nurses. Further 31% of consultants, 29% of nurses and 3% of specialist registrar, had never attended a place of worship. There was no statistically significant difference shown between consultants with or without a personal belief of importance in their attitudes to the withdrawal of life-sustaining treatment and opinion that physician-assisted suicide should be allowed. Statistically significant differences were found between consultants and nurses in their attitudes toward withdrawing treatment and continuing paranteral hydration. Consultants are more likely not to initiate a life sustaining treatment than stopping one that has already been started.

Most nurses strongly agree that nursing responsibilities include addressing spirituality and not leaving the discussion to the hospital chaplain, the patients' priest, minister, or family member. Also, spiritual care assessments for dying patients are significant part of nursing practice. Nurses have a need and desire for greater education, assessment tools and understanding of how to approach the patient and/or family members. Nurses perceive the meaning of spiritual care to them as God and faith, belief and culture, nurturing and peace, comfort, and support (Murray, 2010).

EOL care professionals need to be sensitive to and have an appreciation of various religious traditions in order to meet the unique spiritual needs of patients and families having a variety of religious and cultural backgrounds. The following part of the literature review will shed more lights on two major world religions (Christianity and Islam) and their relation to EOL care.

Christianity is the largest religion in the world (Gibbs and Grey, 2006). For Christian patients, death is a consequence of sin and is a temporary separation of body and

soul, to reach the eternal life, and the dead will be raised and judged at the second coming of Christ. EOL Christian patients may view their illness and death as a punishment and may experience associated feelings of guilt. Also, death anxiety may be evident since no one knows, whether he/she will go to heaven or hell. A good death involves being spiritually prepared, having resolve in interpersonal relationships and reconciling sins. It is important that the dying receive their last rite by a priest or minister, which involves any or all of the following: a) Anointing the sick, b) Reconciliation, and c) Holy Communion. Mourning practices include prayer to God and to the loved one who has died and lighting candles which symbolizes the ignition of the eternal light and love of Christ (Bauer-Wu and Yeager, 2007).

Catholicism, which is a main branch of Christianity, believes that to continue ventilation would be interfering with the process of dying and might be causing some suffering and harm. So, beginning treatment does not necessitate its continuation, particularly if it is deemed to be causing harm as long as the intent is not to cause death per se however, pain management is encouraged, particularly in the case of terminal illness (Clarfield, et al., 2003).

The word Islam means submission to the will of God (Allah). The teaching of Islam represents a unitary monotheistic religious tradition that has been revealed by Allah to the Prophet Muhammad (peace be upon him). Muslims follow the teaching of Prophet Muhammad, who Muslims believe that he was the last prophet from Allah on earth. Islamic scriptures are contained in the Quran, which revealed from Allah to Prophet Muhammad.

The purpose of worldly life, from the Islamic view is to prepare for eternal life. Muslims believe that death is the fate of all living beings, and that it is the beginning of the eternal life. Islam has a well-developed belief about after life spanning, from the time of corporal death to the day of resurrection.

Family and friends provide emotional support, provide Islamic rituals, reading Quran, and care for their dying patients. It is considered a spiritual duty for family members to care for their dying relatives. When the patient is conscious, imminent dying provides final moments for reflection and forgiveness. Family and friends may assist the patient in religious rituals or pray for the soul of the patient when he/she is unconscious. In Islam, it is believed that prayers and charity can be weighted for the dead, and it can reach his/her soul (Bauer-Wu and Yeager, 2007). The Islamic view of Muslim patients toward health and illness corporate the notion of receiving illness and death with patience, mediation, and prayers (Cheraghi et al., 2005).

In the area of decision making at EOL, euthanasia, has no place in Islam. Human life is considered a sacramental value, given by Allah and should be terminated by Allah only (A. Taha, Dar Al-Fatwa, personal communication, August 23, 2011). Disease may be regarded as a test from Allah, but carries tiding of forgiveness and mercy (Cheraghi, et al., 2005). Despite Muslims' believe that all healing comes ultimately from Allah; they also believe that they have duty to seek out medical attention and treatment when ill, and have the right to receive appropriate medical care. Although an observant Muslim would be obligated to accept treatment, one cannot enforce someone to accept life sustaining treatment therapy if they refuse (Clarfield, et al., 2003).

In case of severe pain at EOL, Muslim physicians have advocated the use of narcotic analgesics, but with respect to two important principles. First, Islamic law (sharia) does not allow the physician to use narcotics for the purpose of hastening death. Second, pain and symptom management may have to be balanced against the patient's ability to participate in prayers and other religious rituals in the final moments of life (Bauer-Wu and Yeager, 2007).

For nurses charged with the care of Muslims, an understanding of how their perception of health and illness are influenced by their faith is important. By facilitating religious practices, the dying person and family alike can achieve spiritual fulfillment even in a hospital settings. Nurses who provide care for patients at EOL can utilize religious principles in empowering patient's spirituality and facilitating its practices.

Summery

In summary, terminally ill patients have multi dimensional EOL needs, based on the holistic approach of nursing care. Those needs can be categorized as follows:

- Physical: a focus on balancing pain and other symptoms and on direct care.
- Emotional and psychological: a focus on the ability to cope with a terminal illness, on personal and/or family problems deriving from the illness and on impending death.
- Social: a focus on patients' interpersonal relations within the family, with society and their economic needs.

- Spiritual: a focus on past experiences and the search for meaning in life within religious and cultural ties (Steinhauser, et al., 2000).

There is a wide variation in the views of patients, families, physicians, and nurses in relation to EOL care issues. Those variations emphasize the notion that there is no single accepted definition of EOL needs. The quality EOL care is a dynamic process that require health care professionals' knowledge and common sense, along with constant and strict cooperation with patients and families. The process is mediated by the individual's and family's values, knowledge and care preferences (Natan, et al. 2010).

The reviewed literatures confirm the presence of many obstacles, confronting ICU-RNs in their delivery of EOL care. Helpful behaviors were also identified. The majority of literature focus on the importance of including nurses and families in EOL care decisions as this is often neglected. The spirituality dimension was recognized as an important determinant of patients' and families' behaviors at EOL.

CHAPTER 3

METHOD

In this study, the perceptions of Jordanian intensive care nurses regarding the obstacles and helpful behaviors at EOL were assessed quantitatively. This chapter will discuss the methodological part of the study, including the design, settings, sample and sampling, ethical consideration, instrument, data collection and data analysis.

Design

A descriptive cross-sectional design was used to assess the perception of Jordanian intensive care nurses about the intensity and frequency of helpful behaviors and obstacles related to EOL care. This design was chosen because the study describes an aspect that was not previously investigated in Jordan, which would serve as a starting point for establishing a data base in this field. Also, cross-sectional design addresses the need to document facts by looking at a single phenomenon across multiple population at a single point in time, without any attempt to follow up over time (Houser, 2008, pp. 331; Ruane, 2005, pp. 93). This design can be used to collect data from a selected sample to describe larger population at that time, for the purpose of description as well as determination of relationships between variables (Babbie, 1990, pp. 56).

Descriptive designs can be valuable in documenting the prevalence, nature and intensity of health-related behaviors, and the development of effective interventions (Polit and Beck, 2004, pp. 195). Survey research is frequently conducted for the purpose of making descriptive assertions about some population, to discover the distribution of certain traits, attitudes, opinions or behaviors (Babbie, 1995, pp. 51-52; Sadhu and Singh, 1983,

pp. 31). This design is consistent with the study purpose and helps in answering the research questions.

Settings

This study was conducted in Jordanian hospitals. There are four health sectors in Jordan; private hospitals 57%, governmental 30%, military hospitals 11%, and university hospitals 2% (MOH, 2007, pp. 12). Jordan is divided into three regional clusters; North 28% (of inhabitants), Middle 62%, and south 10% (DOS, 2004b). The selection of hospitals was based on the proportion of ICU-RN within health sectors and regional clusters. The sample was recruited from the intensive care units in the randomly chosen hospitals.

Sample and Sampling

Probability sampling method using the stratified random technique was used to recruit the study sample. Probability sampling provides an efficient method for selecting a sample that should adequately reflect the variation that exists in the population as a whole (Babbie, 1990, pp. 70). Random sampling involves a selection process in which each element in the population has an equal, independent chance of being selected (Polit & Beck, 2004, pp. 295).

Nurses were recruited using the stratified random sampling design. The researcher stratified the sample based on the proportions of nurses within the regional clusters. The effect of stratification is to ensure the proper representation of nurses within their regions and health sector (stratification variables) in order to enhance representation of nurses' perceptions (Babbie, 1995, pp. 87).

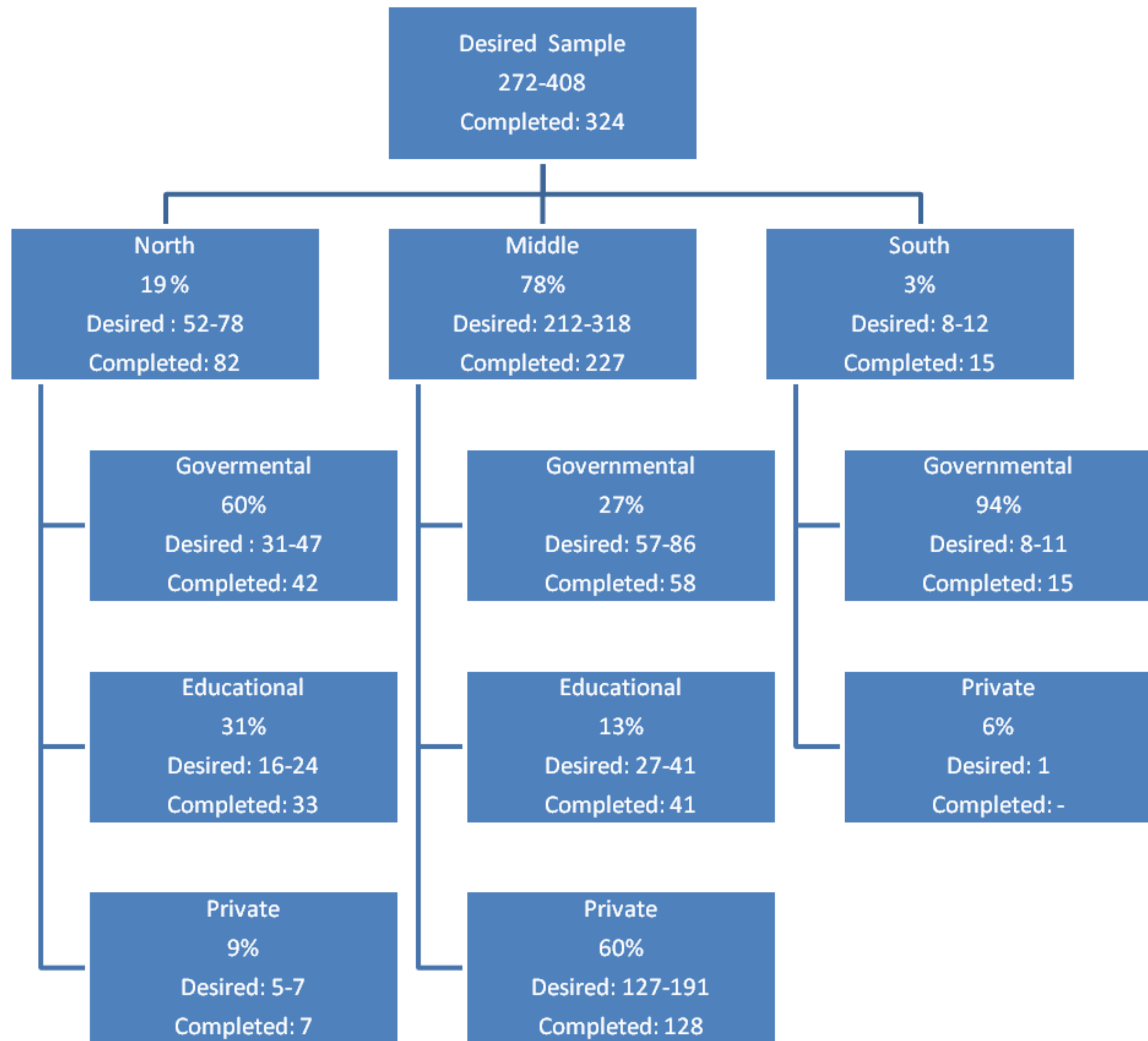
Next, the researcher selected the required number of hospitals in each strata and investigating all the elements in the randomly chosen hospitals. All sectors and regions were included except for military hospitals, since permission was not granted, and other hospitals that do not have ICU like psychiatric and rehabilitation hospitals.

The precise number of ICU-RNs is not formally documented, based on searching the data bases of the Ministry of Health and Department of Statistics. Furthermore the Jordanian Nursing Council and Jordan Nurses and Midwives Council were also contacted and confirmed the absence of those data. Therefore hospitals were contacted directly by the researcher to estimate the number of ICU-RN. The total number of ICU-RN in these hospitals was estimated to be around 930 nurses. The sample was estimated based on 95% confidence level and 5 confidence interval, which revealed a required sample of at least 272 ICU-RNs from all regions (Fowler, 2009). In addition, an addition of up to 50% of the required sample was recruited when possible, to account for sample inflation and to ensure accurate representation. Thus the total required sample size ranged from 272 to 408 ICU-RNs.

Based on the estimated numbers of ICU-RN in the hospitals, it has been found that 78% of ICU-RN work in the Middle region, 19% in the north and 3% in the south, so the minimum desired sample of nurses from each regional cluster was calculated to be 212 ICU-RN from the middle, 52 from the north and 8 from the south. The second level of stratification was based on the health sectors of each regional cluster. In the middle region, the percentages of ICU-RN were as follows: private 60%, governmental 27%, educational 13%, which revealed the need for at least 127 ICU-RN from private sector, 57 ICU-RN from governmental sector and 27 ICU-RN from educational sector. In the north region, the

percentages of ICU-RN were as follows: governmental 60%, educational 31%, and private 9%, which revealed the need for 31 ICU-RN from governmental sector, 16 ICU-RN from educational sector and 5 from private sector. For the south region, all the sample was taken from the governmental sector since its percent reached 94% with absence of any educational hospital and only 6% in private sector that lead to unrepresentative number since the total number of ICU-RN required from the south region was 13. The minimum number of respondents was ensured for each regional cluster and heath sector. Figure 2 below illustrates the sampling method and shows the total desired and actually recruited sample from different regions and sectors.

Figure (2): Sample Distribution in Jordanian Regional Clusters and Health Sectors.



After determining the desired number from each health sector in each regional cluster, hospitals were chosen randomly using flipped papers. The selection was continued until the desired number of ICU-RNs was reached. The final number of hospitals included

in the study was 23 hospitals; in which 16 were in the middle, 5 were in the north, and 2 were in the south.

All ICU-RNs in the randomly chosen hospitals, who were willing to participate, were included in the study. The inclusion criteria include: being registered nurse, working in the ICU, having cared for at least one end of life care patient, and having Jordanian nationality. The total number of ICU RNs included in the study was 324 nurses.

Ethical Considerations

Ethical approval was obtained from the scientific research committee at the Faculty of Nursing at the University of Jordan. Further, approvals from the targeted hospitals individually were obtained before data collection began. For the private and educational hospitals, approvals were granted directly from their research committees, while the approval from the governmental hospitals was granted from the main research committee in the Ministry of Health. After that, approvals from some of the governmental hospitals were also requested based on their internal policies.

Participation in the study was voluntary based on informed consent. The participants were asked to sign the informed consent prior to answering the questionnaire. A cover letter of the questionnaire were provided to clarify the purpose of the study, the anonymity of the respondents, their right to withdraw at anytime, and the confidentiality of the data in which no one, except the researcher will have access to the data. (Appendix A).

Confidentiality of the data was ensured throughout the study. Data were secured correctly, saved in the researcher’s password protected computer. Also, the software containing data were further secured through different passwords. The questionnaires and

any other hard copies related to the study were secured in a cabinet in a locked space. The questionnaires were coded by numbers related to the hospitals, and no one except the researcher knows the coding system or have access to the data.

Permission was obtained from the authors of the questionnaire to adopt and use in the study (Appendix B). Also permission was obtained from the theory developers to use it in the study (Appendix D)

Instrument

The National Survey of Critical Care Nurses regarding End of Life Care by Kirchhoff and Beckstrand (2000), was used in this study. The original questionnaire was modified and used by Beckstrand and Kirchhoff (2005), and further used by Gross (2006) and Crump et al. (2010).

The questionnaire consists of 72 items divided into three parts: demographic data (15 question), four open-ended questions; allowing nurses to add any items or comments, and 53 Likert-type survey questions describing obstacles (29 items) and supportive behaviors (24 items). The demographic data were presented at the end of the questionnaire, asking about years of nursing experience, years of ICU experience, gender, age, level of education, number of ICU patients that the nurse gave immediate EOL care to, type of ICU that the nurse primarily employed, type of facility, nurse's position at the facility, number of beds in the unit, and number of working hours per week as RN.

For each of the 53 items, participants were requested to rate each item for its size and frequency. The size was assessed on 5-level Likert-scale. Responses were: 0 = not an obstacles/not a help, 1 = extremely small, 2 = small, 3 = medium, 4 = Large, 5 = extremely

Large. The frequency of occurrence was also rated on 5-level Likert-scale. Responses were: 0 = never occurs, 1 = almost never occurs, 2 = sometimes occurs, 3 = fairly often occurs, 4 = very often occurs, 5 = always occurs.

In the original study of Kirchhoff and Beckstrand (2000), Cronbach α internal consistency was 0.86 for the obstacle size items and 0.82 for the supportive behavior items. The reliability of the instrument was further tested by Beckstrand and Kirchhoff (2005), who reported a Cronbach α internal consistency of 0.89 for both the 29 obstacle size items and obstacle frequency items, 0.86 for the 24 supportive behavior size items and 0.81for the 24 supportive behavior frequency items. In this study, internal consistency reliability was 0.91 for the 24 help size items, 0.91 for the 24 help frequency items, 0.89 for the 29 obstacle size items, and 0.88 for the 29 obstacle frequency items. The dimensionality and comprehensiveness of the questionnaire items were tested and ensured by the original authors through factor analysis. Also instrument validity was insured (Kirchhoff and Beckstrand, 2000).

Data Collection

Prior to data collection, a pilot study was carried out on about 10% of the sample size. It was used to assess the feasibility of the study in terms of the ease of questionnaire language and format, and time needed to fill the questionnaire which was not mentioned in the previous studies. Data were collected from a convenience sample of 30 ICU-RN who were not later included in the study sample. They all met the inclusion criteria for the study, and were asked to complete the questionnaire and a special evaluation form of the instrument (see Appendix E). The time needed to complete the questionnaire ranged

between 15-25 minutes, with an average of 20 minutes. Almost all respondents in the pilot sample agreed that the instruction provided with the questionnaires were clear and that questionnaire items were clearly understood. There were no ambiguous questions and respondents were not objected to answer any question. Also, respondents agreed that the lay out and presentation of the questionnaire was clear and the questions were consistent with the study purpose. Two respondents only raised concern about the length of the questionnaire.

The targeted hospitals were contacted to ask for their permission to collect data from ICU-RNs. They were asked to assign private room where nurses can fill the questionnaire if possible. The researcher visited the ICUs in the chosen hospitals to meet the head nurses of these units and provide them with information about the purpose of the study and the procedure of data collection.

The study data were collected through self-administered questionnaire. The questionnaire was distributed by the researcher himself to each participant in individual bases. The distributed questionnaires consisted of two parts. The first part included a cover letter describing the study and rights of the participants in addition to the informed consent that have to be signed by the participant before filling the questionnaire (see Appendix A). The second part contained the questionnaire items to be filled. The participants were asked to fill the questionnaires in the assigned private room (when available) or any other private place they choose. They were instructed to submit the completed questionnaires to the head nurse of their departments, in a sealed envelope that was provided by the researcher. The contact information of the researcher was available to participants on the questionnaire, if

respondents have any question or inquiry. Phone calls and site visits were used to remind the nurses and their managers to complete the provided questionnaires.

All of the completed questionnaires were collected and coded based on hospitals. The serials of codes for each hospital were documented in a special form that is available with the researcher only. Data were entered into the Statistical Package for Social Science (SPSS) version 17. Data were entered by the researcher himself and checked by two research assistants. Descriptive statistics were used to examine outliers and missing data. Frequency distribution tables were used to detect any “impossible” score values. Missing data were replaced by the mean score of the corresponding item, after getting sure that this item was not filled in the questionnaire (Warner, 2008). All of the entered data were examined, treated, and cleaned. The hard copies of the completed questionnaires are kept in a key-locked cabinet with the researcher. The confidentiality of the collected questionnaires was ensured all over the study.

Data Analysis

Analysis of data was carried out using the SPSS version 17 and guided by the study’s research questions. Descriptive analysis was used to describe sample characteristics. Years of nursing experience, years of ICU experience, age, numbers of beds in the unit and hours per week nurses work as RN were analyzed using mean, standard deviation, maximum, and minimum. While frequency were used for the categorical questions; level of education, number of patients who received care from the ICU-RN, type of ICU, type of facility, region, the nurse’s position in his/her facility, and gender.

Research questions 1, 2, 3, and 4.

1- Which helpful behaviors in EOL care are perceived by intensive care nurses as the largest?

2- Which helpful behaviors in EOL care are perceived by intensive care nurses as the most frequently occurring?

3- Which of the EOL care obstacles are perceived by intensive care nurses as the largest?

4- Which of the EOL care obstacles are perceived by intensive care nurses as the most frequently occurring?

Frequencies, measures of central tendency and dispersion, and reliability statistics were calculated for all help and obstacle items. Then, items were ranked based on their mean scores to determine which items were perceived to be the largest helps or obstacles and which items were perceived to occur most frequently. For help items, each item's size mean was multiplied by the item's frequency mean to obtain a perceived intensity score. For the obstacle size items, each item's size mean was multiplied by the item's frequency mean to obtain a perceived severity score (Beckstrand and Kirchhoff, 2005). After that, the perceived intensity scores for help items and the perceived severity scores for obstacle items were ranked from highest to lowest.

Research questions 5 and 6

5- Is there a difference in rating EOL helpful behavior in relation to nurses' characteristics (years of ICU experience, age, gender, number of patients received EOL care by nurses, type of facility, region)?

6- Is there a difference in rating EOL obstacles in relation to nurses' characteristics (years of ICU experience, age, gender, number of patients received EOL care by nurses, type of facility, region)?

Demographic characteristics were analyzed to determine its relation with the help and obstacle items. For the ICU experience, the average length of ICU work experience (in years) was used to divide respondents into two groups. One group contained nurses who had the same amount or more than average length of ICU experience, while the other group contained those with less than average. Similarly the age variable was recoded into two groups according to the mean. Frequencies and measures of central tendency and dispersion were calculated for all help and obstacle sizes and frequency items in both groups. Since the normality assumption could not be established (Kolmogrov - Smirnov <0.05), and measurement level of the questionnaire items was assumed to be ordinal, non parametric tests were used to test for significant differences among groups. Mann-Whitney U test was instituted to test for significant differences among the items rated by two groups. Furthermore, Kruskal Wallis test was used to test for significant differences between respondents in rating help and obstacle items based on the number of patients received immediate EOL care from ICU nurses, health sectors (type of facility), and regional clusters.

Summary

This chapter presented the methodology of the study. A descriptive cross-sectional design was used to assess the perception of Jordanian ICU-RNs about the size and frequency of helpful behaviors and obstacles related to EOL care. The study was conducted in randomly chosen Jordanian hospitals. A sample of ICU-RNs was selected based on the proportion of ICU-RNs in each health sector and regional cluster using stratified random sampling design. “The National Survey of Critical Care nurses regarding End of Life Care” questionnaire was used in this study. Prior to data collection, a pilot study was carried out, which revealed the clearness of the questions language and format and the appropriateness of the questionnaire to the study purpose. In addition; ethical considerations, data collection procedures and data analysis were discussed thoroughly.

CHAPTER 4

RESULTS

The previous chapter presented the methodological scheme used in this study including its design, settings, sample and sampling, ethical considerations, instrument, and data collection procedure. The last section of the previous chapter presented data analysis plan and procedures, which will be used to organize the flow of results in this chapter. Therefore, in this chapter, a description of the sample characteristics will be presented at the beginning. Then, results are used to answer all research questions in the sequence they were addressed in the method section. All help and obstacle items were analyzed and ranked based on their means to determine which items were perceived to be the largest helps or obstacles, and which items were perceived to occur more frequently. Also, perceived intensity scores and severity scores were calculated and ranked. Finally, nurses' characteristics were analyzed and compared for the help and obstacle items, to test for any significant differences between groups.

Sample Characteristics

A stratified random sample of ICU-RNs (n = 324), working in 23 hospitals distribute in all Jordanian regions, completed the questionnaires. There were 16 nurses who did not agree to participate in the study and didn't sign the consent. There were 59% males (n = 191) and 41 % females (n = 133). Three hundred sixteen (97.5%) of participants hold baccalaureate degree in nursing as their highest completed level of education and 2.5% (n = 8) had master degree in nursing. Participants were employed in their units as bed side nurse (60.5%), charge nurse (35.2%), clinical nurse specialist (2.5%), and others (1.9%). The

units where participants work were: combined ICU/coronary care unit (CCU) (42.9%), general ICU (36.4%), CCU (6.8%), surgical ICU (4%), medical ICU (3.4%), neuro/neurosurgical ICU (2.8%), cardiovascular ICU (1.2%), and others (2.5%).

Participants were employed in private hospitals (41.7%, n = 135), governmental hospitals (35.5%, n = 115), and university hospitals (22.8%, n = 74). Respondents were from middle (70.1%, n = 227), north (25.3%, n = 82), and south (4.6%, n = 15) regions of Jordan. About 25.3% of nurses (n = 82) gave immediate EOL care to less than 5 patients in their career, 22.8% (n = 74) gave care for 5 to 10 patients, 21.3% (n = 69) gave care for more than 30 patients, 17.9% (n = 58) gave care for 11 to 20 patients, and 12.7 % (n = 41) gave care for 21 to 30 patients. Those findings are displayed in table 1.

Table 1: Frequencies and Percentages for the Characteristics of Jordanian Intensive Care Nurses (N = 324)

Item	Category	Frequency	Percentage
Gender	Male	191	59
	Female	133	41
Highest completed level of education	Bachelor	316	97.5
	Master	8	2.5
The position nurse hold at the facility	Bedside	196	60.5
	Charge nurse	114	35.2
	Clinical nurse specialist	8	2.5
	Others	6	1.9
Type of ICU	Combined ICU/CCU	139	42.9
	General ICU	118	36.4
	CCU	22	6.8

Item	Category	Frequency	Percentage
	Surgical ICU	13	4
	Medical ICU	11	3.4
	Neuro/neurosurgical ICU	9	2.8
	Cardiovascular ICU	4	1.2
	Others	8	2.5
Type of facility	Governmental	115	35.5
	Private	135	41.7
	University	74	22.8
Hospital place (Region)	North	82	25.3
	Middle	227	70.1
	South	15	4.6
Number of ICU patients received immediate EOL care	Less than 5	82	25.3
	Between 5 and 10	74	22.8
	Between 11 and 20	58	17.9
	Between 21 and 30	41	12.7
	More than 30	69	31.3

The age of nurses participated in the study ranged from 22 to 50 years, with a mean of 26.5 years and standard deviation (SD) of 4.13. Participants' years of nursing experience ranged from 1 to 23 years with a mean of 4 years (SD = 3.6). Similarly, participants' years of ICU experience ranged from 1 to 22 years with a mean of 3.34 years (SD = 3.07). The mean hours per week that nurses usually work as RN was 48.73 hours (SD = 8.15), ranging from 30 to 95 hours per week. In relation to beds capacity, the number of intensive care

beds in the nurses' units ranged from 4 to 26 beds with a mean of 11.12 beds (SD = 5.7). These findings are shown in table 2.

Table 2: Ranges, Means, and Standard Deviations for the Characteristics of Jordanian Intensive Care Nurses (N = 324)

Item	Minimum	Maximum	Mean	SD
Age	22	50	26.5	4.13
years of nursing experience as RN	1	23	4	3.6
Years of ICU experience	1	22	3.34	3.07
Hours per week do nurses usually work as RN	30	95	48.73	8.15
Number of beds in the unit	4	26	11.12	5.7

Research Question 1: Helpful Behaviors Perceived as the Largest (Help Size)

An internal consistency estimate of reliability was computed for the help size data. Cronbach's alpha was 0.91 for the 24 help items. On the scale of 0 (not a help) to 5 (extremely large help), mean size scores for the help size items ranged from 2.68 to 3.28. The help items receiving the highest size mean scores were having family members accept that the patient is dying (M = 3.28, SD = 1.18), having support staff to collect all the necessary paper work for you after the patient's death which must be signed by the family before they leave the unit (M = 3.21, SD = 1.25), providing a peaceful dignified bedside scene for family members once the patient has died (M = 3.19, SD = 1.26), having enough time to prepare the family for the expected death of the patient (M = 3.18, SD = 1.23), allowing family members adequate time to be alone with the patient after he or she has died

(M = 3.17, SD = 1.29), and a unit designed so that the family has a place to go to grieve in private (M = 3.17, SD = 1.29).

The remaining 4 items of the top 10 help size items were having agreement between physicians involved in the patient's care about how the direction of care should go (M = 3.11, SD = 1.29), having fellow nurses take care of your other patient (s) while you get away from the unit for a few moments after the death of your patient (M = 3.11, SD = 1.29), letting the social worker or religious leader take primary care of the grieving family (M = 3.1, SD = 1.36), and having one family member be the designated contact person for all other family members regarding patient information (M = 3.09, SD = 1.32).

The least helpful behaviors seen by respondents were having un-licensed personnel available to help care for dying patients (M = 2.68, SD = 1.4), having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient (M = 2.87, SD = 1.39), and having the family physically help with care for the dying patient (M = 2.9, SD = 1.38) (see table 3).

Table 3: Averages for Help Size Items Related to End of Life Care as Reported by Intensive Care Nurses (N = 324).

No	Help Items	M	SD
1	Having family members accept that the patient is dying.	3.28	1.187
2	After the patient's death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit.	3.21	1.258
3	Providing a peaceful, dignified bedside scene for family members once the patient has died.	3.19	1.262
4	Having enough time to prepare the family for the expected death of the patient.	3.18	1.232

No	Help Items	M	SD
5	Allowing family members adequate time to be alone with the patient after he or she has died.	3.17	1.296
6	A unit designed so that the family has a place to go to grieve in private.	3.17	1.290
7	Having agreements between physicians involved in the patient's care about how the direction of care should go.	3.16	1.235
8	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	3.11	1.294
9	Letting the social worker or religious leader take primary care of the grieving family.	3.10	1.359
10	Having one family member be the designated contact person for all other family members regarding patient information.	3.09	1.328
11	Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	3.09	1.369
12	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.05	1.273
13	Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	3.03	1.268
14	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	3.03	1.270
15	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	3.02	1.292
16	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	3.02	1.223
17	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	3.00	1.292
18	Having a support person outside of the work setting who will listen to you after the death of your patient	2.98	1.392
19	Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	2.97	1.301

No	Help Items	M	SD
20	Talking with the patient about his or her feelings and thoughts about dying.	2.93	1.325
21	Allowing families' unlimited access to the dying patient even if it conflicts with nursing care some times.	2.93	1.331
22	Having the family physically help with care for the dying patient.	2.90	1.381
23	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	2.87	1.394
24	Having un-licensed personnel available to help care for dying patients.	2.68	1.404

Research Question 2: Helpful Behaviors Perceived as the Most Frequent (Help Frequency)

An internal consistency estimate of reliability was computed for the help frequency data. Cronbach's alpha was 0.91 for the 24 items. On a scale of 0 (never occurs) to 5 (always occurs), mean frequency scores for the help items ranged from 2.35 to 3.0. The help items receiving the highest mean scores for frequency were having support staff to collect all the necessary paper work for you after the patient's death, which must be signed by the family before they leave the unit (M = 3, SD = 1.25), allowing family members adequate time to be alone with the patient after he or she has died (M = 2.89, SD = 1.24), having agreements between physicians involved in the patient's care about how the direction of care should go (M = 2.88, SD = 1.17), teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her" (M = 2.84, SD = 1.33), having family members thank you or in some other way show appreciation for your care of the patient who has died (M = 2.8, SD = 1.17), and the nurse drawing on

his/her own previous experience with the critical illness or death of a family member (M = 2.77, SD = 1.23).

The remaining 4 items of the top 10 help frequency items were having one family member be the designated contact person for all other family members regarding patient information (M = 2.77, SD = 1.35), allowing families unlimited access to the dying patient even if it conflicts with nursing care sometimes (M = 2.77, SD = 1.23), having enough time to prepare the family for the expected death of the patient (M = 2.77, SD = 1.18), and having fellow nurses take care of your other patient (s) while you get away from the unit for a few moments after the death of your patient (M = 2.77, SD = 1.34).

Helpful behaviors rated as least frequently occurring were having un-licensed personnel available to help care for dying patients (M = 2.35, SD = 1.36), letting the social worker or religious leader take primary care of the grieving family (M = 2.42, SD = 1.4), and having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later (M = 2.47, SD = 1.35) (see table 4).

Table 4: Averages for Help Frequency Items Related to End of Life Care as Reported by Intensive Care Nurses (N = 324)

No	Help Items	M	S D
1	After the patient's death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit.	3.00	1.253
2	Allowing family members adequate time to be alone with the patient after he or she has died.	2.89	1.241
3	Having agreements between physicians involved in the patient's care about how the direction of care should go.	2.88	1.174

No	Help Items	M	S D
4	Teaching families how to act around the dying patient such as saying to them, “She can still hear...it is OK to talk to her.”	2.84	1.332
5	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	2.80	1.173
6	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.77	1.237
7	Having one family member be the designated contact person for all other family members regarding patient information.	2.77	1.348
8	Allowing families unlimited access to the dying patient even if it conflicts with nursing care some times.	2.77	1.234
9	Having enough time to prepare the family for the expected death of the patient.	2.77	1.182
10	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	2.77	1.336
11	Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	2.76	1.323
12	Having a fellow nurse tell you that, “You did all you could for that patient,” or some other words of support.	2.73	1.299
13	Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient’s condition will completely recover.	2.72	1.210
14	Providing a peaceful, dignified bedside scene for family members once the patient has died.	2.69	1.315
15	Having family members accept that the patient is dying.	2.68	1.155
16	Having the physician meet in person with the family after the patient’s death to offer support and validate that all possible care was done.	2.65	1.198
17	Having the family physically help with care for the dying patient.	2.64	1.332
18	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	2.56	1.309
19	Having a support person outside of the work setting who will listen to you after the death of your patient.	2.53	1.375

No	Help Items	M	S D
20	A unit designed so that the family has a place to go to grieve in private.	2.53	1.426
21	Talking with the patient about his or her feelings and thoughts about dying.	2.52	1.386
22	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	2.47	1.345
23	Letting the social worker or religious leader take primary care of the grieving family.	2.42	1.406
24	Having un-licensed personnel available to help care for dying patients.	2.35	1.358

Helpful Behaviors Perceived as the Most Intense (Help Intensity)

The perceived intensity score was calculated for each item (mean help size multiplied by mean help frequency) to determine which items were perceived as the most intense (helpful and frequently occurring). The highest possible perceived intensity score from the data (if the highest rated help was also rated as the most frequent) would be 9.84, while the lowest possible perceived intensity score from the data (if the lowest rated help was also rated as the least frequent) would be 6.29. The actual range of perceived intensity scores for help items was from 6.29 to 9.63. The help items receiving the highest perceived intensity scores were having support staff to collect all the necessary paper work for you after the patient's death, which must be signed by the family before they leave the unit (perceived intensity score = 9.63), allowing family members adequate time to be alone with the patient after he or she has died (perceived intensity score = 9.17), having agreements between physicians involved in the patient's care about how the direction of care should go (perceived intensity score = 9.1), having enough time to prepare the family for the expected death of the patient (perceived intensity score = 8.81), having family members accept that

the patient is dying (perceived intensity score = 8.78), teaching families how to act around the dying patient such as saying to them, “She can still hear...it is OK to talk to her” (perceived intensity score = 8.77), and Having fellow nurses take care of your other patient (s) while you get away from the unit for a few moments after the death of your patient (perceived intensity score = 8.61). The remaining 4 items of the top 10 help intensity items were providing a peaceful, dignified bedside scene for family members once the patient has died (perceived intensity score = 8.59), having one family member be the designated contact person for all other family members regarding patient information (perceived intensity score = 8.55), having family members thank you or in some other way show appreciation for your care of the patient who has died (perceived intensity score = 8.52).

Helpful behaviors with the least intensity scores seen by respondents were having un-licensed personnel available to help care for dying patients (perceived intensity score = 6.29), having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient (perceived intensity score = 7.37), and talking with the patient about his or her feelings and thoughts about dying (perceived intensity score =7.38) (see table 5).

Table 5: Perceived Intensity Scores, Size Means, and Frequency Means for Help Items Related to End of Life Care as Reported by Intensive Care Nurses

No	Help Items	M (Size)	M (F)	PIS
1	After the patient’s death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit.	3.21	3.00	9.6303
2	Allowing family members adequate time to be alone with the patient after he or she has died.	3.17	2.89	9.1758

No	Help Items	M (Size)	M (F)	PIS
3	Having agreements between physicians involved in the patient's care about how the direction of care should go.	3.16	2.88	9.1002
4	Having enough time to prepare the family for the expected death of the patient.	3.18	2.77	8.8097
5	Having family members accept that the patient is dying.	3.28	2.68	8.7812
6	Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	3.09	2.84	8.7734
7	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	3.11	2.77	8.6121
8	Providing a peaceful, dignified bedside scene for family members once the patient has died.	3.19	2.69	8.5989
9	Having one family member be the designated contact person for all other family members regarding patient information.	3.09	2.77	8.5543
10	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.05	2.80	8.5270
11	Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	3.03	2.76	8.3629
12	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	3.00	2.77	8.3326
13	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	3.02	2.73	8.2628
14	Allowing families unlimited access to the dying patient even if it conflicts with nursing care some times.	2.93	2.77	8.1005
15	Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	2.97	2.72	8.0742
16	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	3.03	2.65	8.0367
17	A unit designed so that the family has a place to go to grieve in private.	3.17	2.53	8.0320
18	Having the family physically help with care for the dying patient.	2.90	2.64	7.6642

No	Help Items	M (Size)	M (F)	PIS
19	Having a support person outside of the work setting who will listen to you after the death of your patient.	2.98	2.53	7.5549
20	Letting the social worker or religious leader take primary care of the grieving family.	3.10	2.42	7.4887
21	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	3.02	2.47	7.4514
22	Talking with the patient about his or her feelings and thoughts about dying.	2.93	2.52	7.3768
23	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	2.87	2.56	7.3699
24	Having un-licensed personnel available to help care for dying patients.	2.68	2.35	6.2913

PIS: Perceived intensity scores, M: Mean, F: Frequency.

Research Question 3: Obstacles Perceived as the Largest (Obstacle Size)

An internal consistency estimate of reliability was computed for the obstacle size data. Cronbach's alpha was 0.89 for the 29 obstacle items. On the scale of 0 (not an obstacle) to 5 (extremely large obstacle), mean size scores for the obstacle size items ranged from 2.55 to 3.43. The obstacle size items receiving the highest mean scores were the nurse having to deal with angry family members (M = 3.43, SD = 1.3), the nurse having to deal with confused family members while still providing care for the patient (M = 3.32, SD = 1.32), unit visiting hours that are too liberal (M = 3.25, SD = 1.3), family members not understanding what "lifesaving measures" really mean (M = 3.25, 1.19), physicians who are evasive and avoid having conversations with family members (M = 3.2, SD =

1.28), and poor design of units which do not allow for privacy of dying patients or grieving family members (M = 3.18, SD = 1.37).

Another three items were perceived from the top 10 obstacle size items. They include family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information, families not accepting what the physician is telling them about the patient's poor prognosis, and multiple physicians, involved with one patient, who differ in opinion about the direction care should go. The mean of these items were the same (M = 3.16), but with different standard deviations (SD = 1.31, 1.26, and 1.25 respectively). The 10th item of the obstacle size was not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life (M = 3.12, SD = 1.3).

The lowest scoring obstacle size items were unit visiting hours that are too restrictive (M = 2.55, SD = 1.55), physicians who won't allow the patient to die from the disease process (M = 2.82, SD = 1.29), and the nurse knowing about the patient's poor prognosis before the family is told the prognosis (M = 2.83, SD = 1.5) (see table 6).

Table 6: Averages for Obstacle Size Items Related to End of Life Care as Reported by Intensive Care Nurses (N = 324)

No	Obstacle Items	M	SD
1	The nurse having to deal with angry family members.	3.43	1.297
2	The nurse having to deal with confused family members while still providing care for the patient.	3.32	1.322
3	Unit visiting hours that are too liberal.	3.25	1.297
4	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.25	1.187

No	Obstacle Items	M	SD
5	Physicians who are evasive and avoid having conversations with family members.	3.20	1.286
6	Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.18	1.372
7	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	3.16	1.308
8	Families not accepting what the physician is telling them about the patient's poor prognosis.	3.16	1.257
9	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	3.16	1.255
10	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.12	1.301
11	Intra-family fighting about whether to continue or stop life support.	3.06	1.301
12	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	3.06	1.427
13	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.03	1.287
14	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.02	1.321
15	Lack of nursing education and training regarding family grieving and quality end-of-life care.	3.02	1.332
16	The family, for whatever reason, is not with the patient when he or she is dying.	2.98	1.216
17	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.98	1.249
18	The unavailability of an ethics board or committee to review difficult patient cases.	2.97	1.306
19	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	2.96	1.159

No	Obstacle Items	M	SD
20	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	2.95	1.202
21	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	2.94	1.196
22	The patient having pain that is difficult to control or alleviate.	2.91	1.335
23	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	2.91	1.340
24	Dealing with the cultural differences that used by families in grieving for their dying family member.	2.90	1.364
25	No available support person for the family such as a social worker or religious leader.	2.90	1.380
26	Physicians who are overly optimistic to the family about the patient surviving.	2.84	1.319
27	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	2.83	1.496
28	Physicians who won't allow the patient to die from the disease process.	2.82	1.292
29	Unit visiting hours that are too restrictive.	2.55	1.548

Research Question 4: Obstacles Perceived as the Most Frequent (Obstacle Frequency)

An internal consistency estimate of reliability was computed for the obstacles frequency data. Cronbach's alpha was 0.88 for the 29 obstacle items. On the scale of 0 (never occurs) to 5 (always occurs), mean frequency scores for the obstacle items ranged from 2.67 to 3.27. The obstacle frequency items receiving the highest mean scores were family members not understanding what "lifesaving measures" really mean (M = 3.27, SD = 1.21), family and friends who continually call the nurse wanting an update on the

patient's condition rather than calling the designated family member for information (M = 3.23, SD = 1.32), the nurse having to deal with angry family members (M = 3.23, SD = 1.33), poor design of units which do not allow for privacy of dying patients or grieving family members (M = 3.22, SD = 1.37), the nurse knowing about the patient's poor prognosis before the family is told the prognosis (M = 3.15, SD = 1.41), and the nurse having to deal with confused family members while still providing care for the patient (M = 3.15, SD = 1.3).

Another four obstacle items were perceived by respondents as frequently occurring like not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life (M = 3.09, SD = 1.3), continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort (M = 3.07, SD = 1.34), when the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered (M = 3, SD = 1.29), and the family, for whatever reason, is not with the patient when he or she is dying (M = 3, SD = 1.19).

The lowest scoring obstacle size items were employing life sustaining measures at the families' request even though the patient had signed '*advanced directives*' requesting no such treatment (M = 2.67, SD = 1.24), intra-family fighting about whether to continue or stop life support (M = 2.72, SD = 1.33), and no available support person for the family such as a social worker or religious leader (M = 2.76, SD = 1.50) (see table 7).

Table 7: Averages for Obstacle Frequency Items Related to End of Life Care as Reported by Intensive Care Nurses (N = 324)

No	Obstacle Items	M	SD
1	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.27	1.213
2	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	3.23	1.319
3	The nurse having to deal with angry family members.	3.23	1.334
4	Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.22	1.371
5	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	3.15	1.408
6	The nurse having to deal with confused family members while still providing care for the patient.	3.15	1.303
7	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.09	1.304
8	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.07	1.337
9	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.00	1.291
10	The family, for whatever reason, is not with the patient when he or she is dying.	3.00	1.193
11	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	2.99	1.205
12	Families not accepting what the physician is telling them about the patient's poor prognosis.	2.99	1.232
13	Unit visiting hours that are too liberal.	2.95	1.331
14	The unavailability of an ethics board or committee to review difficult patient cases.	2.94	1.305

No	Obstacle Items	M	SD
15	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	2.93	1.240
16	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	2.91	1.257
17	Dealing with the cultural differences that used by families in grieving for their dying family member.	2.87	1.340
18	Unit visiting hours that are too restrictive.	2.86	1.507
19	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.86	1.249
20	Physicians who are evasive and avoid having conversations with family members.	2.85	1.224
21	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	2.83	1.327
22	Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.81	1.292
23	The patient having pain that is difficult to control or alleviate.	2.80	1.226
24	Physicians who are overly optimistic to the family about the patient surviving.	2.80	1.282
25	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	2.79	1.404
26	Physicians who won't allow the patient to die from the disease process.	2.77	1.323
27	No available support person for the family such as a social worker or religious leader.	2.76	1.500
28	Intra-family fighting about whether to continue or stop life support.	2.72	1.325
29	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	2.67	1.239

Obstacles Perceived as the Most Sever (Obstacle Severity)

The perceived severity score was calculated for each item (mean obstacle size multiplied by mean obstacle frequency) to determine which items were perceived as most helpful and most frequent at the same time. The highest possible perceived severity score from the data (if the highest rated obstacle was also rated as the most frequent) would be 11.21, while the lowest possible perceived severity score from the data (if the lowest rated obstacle was also rated as the least frequent) would be 6.8. The actual range of perceived severity scores for obstacle items was from 7.31 to 11.07. The help items receiving the highest perceived severity scores were the nurse having to deal with angry family members (perceived severity score = 11.07), family members not understanding what “lifesaving measures” really mean (perceived severity score = 10.63), the nurse having to deal with confused family members while still providing care for the patient (perceived severity score = 10.44), poor design of units which do not allow for privacy of dying patients or grieving family members (perceived severity score = 10.24), family and friends who continually call the nurse wanting an update on the patient’s condition rather than calling the designated family member for information (perceived severity score = 10.23), and not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient’s life (perceived severity score = 10.23).

The remaining 4 items of the top 10 obstacle severity items were unit visiting hours that are too liberal (perceived severity score = 9.59), families not accepting what the physician is telling them about the patient’s poor prognosis (perceived severity score = 9.45), continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort (perceived severity score = 9.29), and multiple physicians,

involved with one patient, who differ in opinion about the direction care should go (perceived severity score = 9.28).

Obstacles with the least severity scores were unit visiting hours that are too restrictive (perceived severity score = 7.31), employing life sustaining measures at the families' request even though the patient had signed '*advanced directives'* requesting no such treatment (perceived severity score = 7.83), and physicians who won't allow the patient to die from the disease process (perceived severity score = 7.83) (see table 8).

Table 8: Perceived Severity Scores, Size Means, and Frequency Means for Obstacle Items Related to End of Life Care as Reported by Intensive Care Nurses

No	PSS	M (Size)	M (F)	PSS
1	The nurse having to deal with angry family members.	3.43	3.23	11.0696
2	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	3.25	3.27	10.6328
3	The nurse having to deal with confused family members while still providing care for the patient.	3.32	3.15	10.4447
4	Poor design of units which do not allow for privacy of dying patients or grieving family members.	3.18	3.22	10.2436
5	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	3.16	3.23	10.2328
6	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.12	3.09	9.6403
7	Unit visiting hours that are too liberal.	3.25	2.95	9.5886
8	Families not accepting what the physician is telling them about the patient's poor prognosis.	3.16	2.99	9.4517
9	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.02	3.07	9.2888
10	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	3.16	2.93	9.2759

No	PSS	M (Size)	M (F)	PSS
11	Physicians who are evasive and avoid having conversations with family members.	3.20	2.85	9.1376
12	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.03	3.00	9.1019
13	The family, for whatever reason, is not with the patient when he or she is dying.	2.98	3.00	8.9444
14	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	2.83	3.15	8.9372
15	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	2.96	2.99	8.8615
16	The unavailability of an ethics board or committee to review difficult patient cases.	2.97	2.94	8.7242
17	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	2.95	2.91	8.5967
18	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	3.06	2.79	8.5434
19	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.98	2.86	8.5219
20	Lack of nursing education and training regarding family grieving and quality end-of-life care.	3.02	2.81	8.4879
21	Dealing with the cultural differences that used by families in grieving for their dying family member.	2.90	2.87	8.3366
22	Intra-family fighting about whether to continue or stop life support.	3.06	2.72	8.3253
23	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	2.91	2.83	8.2464
24	The patient having pain that is difficult to control or alleviate.	2.91	2.80	8.1652
25	No available support person for the family such as a social worker or religious leader.	2.90	2.76	8.0142
26	Physicians who are overly optimistic to the family about the patient surviving.	2.84	2.80	7.9401
27	Physicians who won't allow the patient to die from the disease process.	2.82	2.77	7.8272

No	PSS	M (Size)	M (F)	PSS
28	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	2.94	2.67	7.8272
29	Unit visiting hours that are too restrictive.	2.55	2.86	7.3108

PSS: Perceived severity score, M: Mean, F: Frequency

Research Questions 5 and 6: Differences between Respondents' Perceptions in Relation to their Characteristics.

Years of intensive care unit experience.

The average years of ICU experience reported by respondents was 3.34 years, ranged from 1 to 22 years. Based on the mean age, the sample was divided into two groups. One group contained nurses who had 3.34 or more years of experience (n = 98) while the other group contained those who had less than 3.34 years of ICU experience (n = 226). Mann-Whitney U test was used to evaluate whether nurses with 3.34 years of ICU experience or more differs from those with less than 3.34 years of ICU experience in their perception of helpful behaviors and obstacles related to EOL care.

The results of this study revealed no significant differences between nurses with less ICU experience and nurses with more ICU experience in relation to their perception of help size and help frequency items. For the obstacle size items, nurses with less ICU experience perceived "continuing to provide advanced treatments to dying patients because of financial benefits to the hospital" larger than nurses with more ICU experience did (Mann-Whitney U = 9452.50, p = 0.032). The obstacle frequency item "pressure to limit family grieving after the patient's death to accommodate a new admit to that room" was

perceived by nurses with more ICU experience to occur more frequently than was perceived by nurses with less ICU experience (Mann-Whitney U = 9440.00, p = 0.03). These findings are illustrated in table 9.

Table 9: Significant Findings of the Mann-Whitney U Test for the Help and Obstacle Items between Nurses with less than 3.34 years of ICU experience (n = 226), and Nurse with 3.34 years of ICU Experience or more (n = 98)

Category	Item	Groups	Mean rank	Sum of ranks	U	W	Z	P value
Obstacle size	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	<3.34	169.67	38346.50	9452.50	14303.50	-2.15	.032
		≥3.34	145.95	14303.50				
Obstacle frequency	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	<3.34	155.27	35091.00	9440.00	35091.00	-2.17	.030
		≥3.34	179.17	17559.00				

U: Mann-Whitney U test, W: Wilcoxon W test

Age.

The mean age of participants was 26.5 years, ranging from 22 to 50 years. Based on participants' age distribution, the sample was divided into two groups. One group contained nurses of less than 26.5 years old (n = 203), while the other group contained those with 25.6 years old or more (n = 121). Mann-Whitney U test was used to evaluate whether nurses of less than 26.5 years old differ from nurses 26.5 years old or more.

Nurses 26.5 years old or more perceived the help size item "letting the social worker or religious leader take primary care of the grieving family" as more helpful in providing EOL care than nurses of less than 26 years old (Mann-Whitney U = 10485.50, p = 0.024). Also, older nurses perceived the obstacle size items "multiple physicians,

involved with one patient, who differ in opinion about the direction care should go” and “continuing to provide advanced treatments to dying patients because of financial benefits to the hospital” larger than younger nurse did (Mann-Whitney U = 10515.00, p = 0.026; Mann-Whitney U = 10573.00, p = 0.032 respectively), while the obstacle frequency items “pressure to limit family grieving after the patient’s death to accommodate a new admit to that room” and “the unavailability of an ethics board or committee to review difficult patient cases” were perceived by younger nurses to occur more frequently(Mann-Whitney U = 9309.50, p = <0.001; Mann-Whitney U = 10693.00, p = 0.046 respectively). No significant differences were found between the two groups in relation to help frequency items. Table 10 illustrates the significant findings for the Mann-Whitney test.

Table: 10: Significant Findings of the Mann-Whitney U Test for the Help and Obstacle Items between Nurses of Less than 26.5 Years (n = 203), and Nurses 26.5 Years or More, (n = 121).

Category	Item	Groups	Mean Rank	Sum of Ranks	U	W	Z	P value
Help size	Letting the social worker or religious leader take primary care of the grieving family.	<26.5	153.65	31191.50	10485.50	31191.50	-2.26	.024
		≥26.5	177.34	21458.50				
Obstacle size	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	<26.5	171.20	34754.00	10515.00	17896.00	-2.23	.026
		≥26.5	147.90	17896.00				
	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	<26.5	170.92	34696.00	10573.00	17954.00	-2.15	.032
		≥26.5	148.38	17954.00				
Obstacle frequency	Pressure to limit family grieving after the patient’s	<26.5	147.86	30015.50	9309.50	30015.50	-3.75	.000

Category	Item	Groups	Mean Rank	Sum of Ranks	U	W	Z	P value
	death to accommodate a new admit to that room.	≥26.5	187.06	22634.50				
	The unavailability of an ethics board or committee to review difficult patient cases.	<26.5	154.67	31399.00	10693.00	31399.00	-1.99	.046
		≥26.5	175.63	21251.00				

U: Mann-Whitney U test, W: Wilcoxon W test

Gender.

Non parametric tests (Mann-Whitney U test) were used to compare between male and female nurses responses of the study items. Male nurses constituted 59% of respondents (n = 191), while female nurses were 41% of respondents (n = 133). For the help size category, two items were perceived significantly different between male and female nurses. "Providing a peaceful, dignified bedside scene for family members once the patient has died" (Mann-Whitney U = 11055.50, p = 0.041), and "having a fellow nurse tell you that, you did all you could for that patient, or some other words of support" (Mann-Whitney U = 10120.00, p = 0.001), were perceived by female nurses as larger helps than male nurses. The help frequency item "a unit designed so that the family has a place to go to grieve in private" was perceived by male nurses to occur more frequently than what perceived by female nurses (Mann-Whitney U = 11054.00, p = 0.043). For the obstacle size items, "being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients" was perceived by female nurses as a larger obstacle than what perceived by male nurses (Mann-Whitney U =

11058.00, p = 0.041). Two obstacle frequently items were perceived to differ significantly between nurses in relation to gender. "Families not accepting what the physician is telling them about the patient's poor prognosis" and "continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family" were perceived by male nurses to occur more frequently than what perceived by female nurses (Mann-Whitney U = 11090.00, p = 0.045; Mann-Whitney U = 10954.00, p = 0.031 respectilvly). The significant differences are presented in table 11.

Table 11: Significant Findings of the Mann-Whitney U test for the Help and Obstacle Items between Male (n = 191) and Female (n = 133) Intensive Care Unit Nurses.

Category	Item	Groups	Mean rank	Sum of ranks	U	W	Z	P value
Help size	Providing a peaceful, dignified bedside scene for family members once the patient has died.	Male	153.88	29391.50	11055.50	29391.50	-2.05	.041
		Female	174.88	23258.50				
	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	Male	148.98	28456.00	10120.00	28456.00	-3.19	.001
		Female	181.91	24194.00				
Help frequency	A unit designed so that the family has a place to go to grieve in private.	Male	171.13	32685.00	11054.00	19965.00	-2.03	.043
		Female	150.11	19965.00				

Category	Item	Groups	Mean rank	Sum of ranks	U	W	Z	P value
Obstacle size	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	Male	153.90	29394.00	11058.00	29394.00	-2.05	.041
		Female	174.86	23256.00				
Obstacle frequency	Families not accepting what the physician is telling them about the patient's poor prognosis.	Male	170.94	32649.00	11090.00	20001.00	-2.00	.045
		Female	150.38	20001.00				
	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	Male	171.65	32785.00	10954.00	19865.00	-2.16	.031
		Female	149.36	19865.00				

U: Mann-Whitney U test, W: Wilcoxon W test

Number of patients received immediate end-of-life care from ICU nurses.

The number of patients that ICU nurses gave immediate EOL care was categorized into five groups based on their frequency distribution: less than 5 patients (25.3%, n = 82), between 5 and 10 patients (22.8%, n = 74), between 11 and 20 patients (17.9%, n = 58), between 21 and 30 patients (12.7, n = 41), and more than 30 patients (21.3%, n = 69). Kruskal Wallis test was used to compare nurses' perception of the helpful behaviors and obstacles for EOL care in relation to the number of patients they gave immediate EOL care.

In the help size item category, three items were perceived differently between nurses in relation to the number of EOL patients they gave immediate EOL care. Nurses who provide care for more than 11 EOL patients perceived the item “letting the social worker or religious leader take primary care of the grieving family” as a larger help than nurses who provide EOL care to 10 patients or less ($p = 0.013$). For the help frequency category, four items were significantly different between nurses in relation to the number of EOL patients they gave immediate EOL care. These items were “having enough time to prepare the family for the expected death of the patient” ($p = 0.023$), “allowing family members adequate time to be alone with the patient after he or she has died” ($p = 0.003$), “having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later” ($p = 0.017$), and “having un-licensed personnel available to help care for dying patients” ($p = 0.013$).

For the obstacle category as a whole, it can be obviously seen that nurses who provide immediate EOL care to more patients rated obstacle size and frequency items higher than nurses who cared for fewer patients. In the obstacle size category, two items were significantly different between groups. They were “continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient’s family” ($p = 0.036$), and “the nurse having to deal with angry family members” ($p = 0.006$). The obstacle frequency item “family members not understanding what “life-saving measures” really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won’t allow the patient to talk, or that ribs may be broken during chest compressions” ($p = 0.004$) was perceived to occur more frequently by nurses who provided care to more EOL patients. The significant findings are presented in table 12.

Table 12: Statistically Significant Differences of Kruskal Wallis Test for Help and Obstacle Items Reported by Intensive Care Nurses Based on the Number of Patients Received Immediate End-of-Life Care from ICU Nurses: Less than 5 Patients (n = 82), between 5 and 10 Patients (n = 74), Between 11 and 20 patients (n = 58), Between 21 and 30 Patients (n = 41), and more than 30 Patients (n = 69).

Category	Item	Groups	Mean rank	P value
Help size	Letting the social worker or religious leader take primary care of the grieving family.	Less than 5	143.77	.013
		Between 5 and 10	143.89	
		Between 11 and 20	180.34	
		Between 21 and 30	175.95	
		More than 30	181.72	
	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	Less than 5	137.48	.019
		Between 5 and 10	170.47	
		Between 11 and 20	189.04	
		Between 21 and 30	157.98	
		More than 30	164.06	
	After the patient's death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit.	Less than 5	142.23	.038
		Between 5 and 10	159.36	
		Between 11 and 20	190.45	
		Between 21 and 30	172.91	
		More than 30	160.28	
Help frequency	Having enough time to prepare the family for the expected death of the patient.	Less than 5	134.85	.023
		Between 5 and 10	159.02	
		Between 11 and 20	157.00	
		Between 21 and 30	177.17	
		More than 30	195.00	
	Allowing family members adequate time to be alone with the patient after he or she has died.	Less than 5	134.07	.003
		Between 5 and 10	152.65	
		Between 11 and 20	180.97	
		Between 21 and 30	172.51	
		More than 30	185.37	
	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	Less than 5	171.15	.017
		Between 5 and 10	164.08	
		Between 11 and 20	163.10	
		Between 21 and 30	191.27	
		More than 30	132.93	
	Having un-licensed personnel available to help care for dying patients.	Less than 5	172.38	.013
		Between 5 and 10	171.31	
		Between 11 and 20	162.68	

Category	Item	Groups	Mean rank	P value
		Between 21 and 30	182.50	
		More than 30	129.28	
Obstacle size	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	Less than 5	139.77	.036
		Between 5 and 10	154.32	
		Between 11 and 20	178.31	
		Between 21 and 30	171.15	
		More than 30	179.86	
	The nurse having to deal with angry family members.	Less than 5	132.83	.006
		Between 5 and 10	166.37	
		Between 11 and 20	164.07	
		Between 21 and 30	170.65	
		More than 30	187.45	
Obstacle frequency	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	Less than 5	136.76	.011
		Between 5 and 10	153.75	
		Between 11 and 20	179.91	
		Between 21 and 30	186.59	
		More than 30	173.52	
	Unit visiting hours that are too restrictive.	Less than 5	161.54	.043
		Between 5 and 10	136.25	
		Between 11 and 20	181.11	
		Between 21 and 30	163.06	
		More than 30	175.82	
	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	Less than 5	147.26	.001
		Between 5 and 10	135.89	
		Between 11 and 20	175.15	
		Between 21 and 30	202.54	
		More than 30	174.72	
	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	Less than 5	145.07	.019
		Between 5 and 10	151.84	
		Between 11 and 20	190.63	
		Between 21 and 30	152.24	
		More than 30	177.09	
	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	Less than 5	139.91	.014
		Between 5 and 10	161.53	
		Between 11 and 20	155.16	
		Between 21 and 30	172.01	
		More than 30	190.91	
	Family members not	Less than 5	131.75	.004

Category	Item	Groups	Mean rank	P value
	understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	Between 5 and 10	162.12	
		Between 11 and 20	171.49	
		Between 21 and 30	170.07	
		More than 30	187.39	
	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	Less than 5	138.84	.041
		Between 5 and 10	179.52	
		Between 11 and 20	158.86	
		Between 21 and 30	181.44	
		More than 30	164.17	
	The nurse having to deal with angry family members.	Less than 5	134.85	.001
		Between 5 and 10	159.02	
		Between 11 and 20	157.00	
		Between 21 and 30	177.17	
		More than 30	195.00	

Health sectors (type of facility).

Participants were employed in three different sectors: private hospitals (41.7%, n=135), governmental hospitals (35.5%, n=115), and university hospitals (22.8%, n=74). In order to assess the effect of facility type on nurses' perceptions of helpful behaviors and obstacles for EOL care, Kruskal Wallis test was used. For the help size category, four items were perceived significantly different between nurses who work in governmental, private, and university hospitals. The help size item "having one family member be the designated contact person for all other family members regarding patient information" was perceived by nurses who work in private hospitals as a larger help followed by nurses who work in university hospitals and governmental hospitals respectively ($p = 0.002$). For the help frequency category, four items were also perceived significantly different between nurses

based on the type of facility they employed in. University hospitals' nurses perceived the item "letting the social worker or religious leader take primary care of the grieving family" to occur more frequently than private hospitals' nurses and governmental hospitals' nurses did (p = 0.022).

For the obstacle size items, six items were perceived significantly different between groups. Governmental hospitals' nurses perceived the item "unit visiting hours that are too restrictive" as a larger obstacle than private and university hospitals' nurses (p = 0.045). The obstacle frequency items "physicians who are overly optimistic to the family about the patient surviving" and "the nurse knowing about the patient's poor prognosis before the family is told the prognosis" (p = 0.013, 0.034 respectively). Both items were perceived by private hospitals' nurses to occur more frequently, followed by university hospitals' nurses and governmental hospitals' nurses respectively. The significant findings are presented in table 13.

Table 13: Statistically Significant Differences of Kruskal Wallis Test for Help and Obstacle Items Reported by Intensive Care Nurses Based on the Type of Facility they are Employed in: Governmental (n = 115), Private (n = 135), and University Hospitals (n = 74).

Category	Item	Groups	Mean rank	P value
Help size	Having one family member be the designated contact person for all other family members regarding patient information.	Governmental	139.87	.002
		Private	180.81	
		University	164.25	
	Letting the social worker or religious leader take primary care of the grieving family.	Governmental	159.96	.049
		private	152.56	

Category	Item	Groups	Mean rank	P value
		University	184.59	
	Allowing family members adequate time to be alone with the patient after he or she has died.	Governmental	142.10	.011
		Private	175.69	
		University	170.14	
	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	Governmental	142.58	.009
		Private	178.06	
		University	165.07	
Help frequency	Having the family physically help with care for the dying patient.	Governmental	147.83	.011
		Private	160.81	
		University	188.38	
	Talking with the patient about his or her feelings and thoughts about dying.	Governmental	171.77	.024
		Private	146.27	
		University	177.69	
	Letting the social worker or religious leader take primary care of the grieving family.	Governmental	149.55	.022
		Private	160.12	
		University	186.97	

Category	Item	Groups	Mean rank	P value
	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	Governmental	146.27	.023
		Private	165.19	
		University	182.82	
Obstacle size	Unit visiting hours that are too restrictive.	Governmental	179.15	.045
		Private	156.20	
		University	148.13	
	Lack of nursing education and training regarding family grieving and quality end-of-life care.	Governmental	158.89	.050
		Private	153.30	
		University	184.90	
	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	Governmental	143.93	.019
		Private	169.61	
		University	178.36	
	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	Governmental	140.68	.003
		Private	179.41	
		University	165.56	
	The family, for whatever reason, is not with the patient when he or she is dying.	Governmental	178.04	.047

Category	Item	Groups	Mean rank	P value
		Private	158.20	
		University	146.20	
	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	Governmental	143.48	.007
		Private	179.96	
		University	160.21	
	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	Governmental	145.62	.016
		Private	178.56	
		University	159.43	
Obstacle frequency	Physicians who are overly optimistic to the family about the patient surviving.	Governmental	147.00	.013
		Private	179.56	
		University	155.45	
	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	Governmental	144.91	.034
		Private	174.24	
		University	168.42	

Regional clusters.

As previously described, Jordan is divided into three regional clusters from which our respondents were obtained. Respondents were from middle (70.1%, n=227), north (25.3%, n=82), and south region of Jordan (4.6%, n=15). Those regions were used to test their effect on the participants' perception of EOL care. Three help size items were perceived significantly different between nurses who work in north, middle, and south regions. "Having agreements between physicians involved in the patient's care about how the direction of care should go" ($p = 0.034$), "having the family physically help with care for the dying patient" ($p = 0.041$), and "having family members accept that the patient is dying" ($p = 0.036$), were rated higher by nurses who work in the middle region than others. For the help frequency category, seven items (see table 14) were perceived significantly different between nurses in relation to their regional clusters.

For the obstacle size items, six items (see table 14) were perceived significantly different between groups. For example, the item "when the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered" was perceived as a larger obstacle by nurses working in the middle region followed by nurses working in the north and south region ($p<0.001$). For the obstacle frequency category, four items were perceived significantly different between groups. Those items are "the unavailability of an ethics board or committee to review difficult patient cases" ($p = 0.024$), "unit visiting hours that are too liberal" ($p = 0.011$), "continuing to provide advanced treatments to dying patients because of financial benefits to the hospital" ($p = 0.040$), and "when the nurses' opinion about the direction patient care should go is not requested, not

valued, or not considered" (p = 0.002). Table 14 shows the significant findings using Kruskal Wallis test.

Table 14: Statistically Significant Differences of Kruskal Wallis Test for Help and Obstacle Items Reported by Intensive Care Nurses Based on their Regional Clusters: North (n = 82), Middle (n = 227), and South (n = 15).

Category	Item	Groups	Mean rank	P value
Help size	Having agreements between physicians involved in the patient's care about how the direction of care should go.	North	152.40	.034
		Middle	169.41	
		South	113.07	
	Having the family physically help with care for the dying patient.	North	141.82	.041
		Middle	170.83	
		South	149.57	
	Having family members accept that the patient is dying.	North	140.89	.036
		Middle	170.74	
		South	155.93	
Help Frequency	A unit designed so that the family has a place to go to grieve in private.	North	184.53	.028
		Middle	156.43	
		South	133.93	
	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	North	195.43	.001
		Middle	151.81	
		South	144.20	
	Talking with the patient about his or her feelings and thoughts about dying.	North	190.29	.006
		Middle	153.22	
		South	150.93	
	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	North	160.12	.018
		Middle	159.05	
		South	227.70	
	Having a support person outside of the work setting who will listen to you after the death of your patient.	North	185.61	.030
		Middle	154.46	
		South	157.87	
	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	North	190.71	.003
		Middle	151.24	
		South	178.67	
	Having un-licensed personnel available to help care for dying patients.	North	192.43	.003
		Middle	151.76	
		South	161.37	
Obstacle	Not enough time to provide quality end-	North	143.29	.010

Category	Item	Groups	Mean rank	P value
size	of-life care because the nurse is consumed with activities that are trying to save the patient's life.	Middle	172.13	
		South	121.87	
	The unavailability of an ethics board or committee to review difficult patient cases.	North	141.24	.025
		Middle	167.90	
		South	197.00	
	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	North	145.50	.032
		Middle	170.86	
		South	128.93	
	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	North	131.68	.001
		Middle	174.47	
		South	149.83	
	Physicians who are evasive and avoid having conversations with family members.	North	141.15	.006
		Middle	172.82	
		South	123.00	
	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	North	129.79	.000
		Middle	176.83	
		South	124.43	
Obstacle frequency	The unavailability of an ethics board or committee to review difficult patient cases.	North	177.01	.024
		Middle	154.33	
		South	206.87	
	Unit visiting hours that are too liberal.	North	146.89	.011
		Middle	171.41	
		South	112.93	
	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	North	184.17	.040
		Middle	156.01	
		South	142.23	
	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	North	134.21	.002
		Middle	174.22	
		South	139.80	

Summery

This chapter presented the results for descriptive and inferential statistics conducted in the study. Three hundred and twenty four ICU-RNs working in 23 hospitals from three health sectors distributed over the three Jordanian regions were included in the study. They were surveyed to assess their perception of the helpful behaviors and obstacles surrounding EOL care. Sample characteristics were presented based on the analysis of demographic data. Ranking of means were used to answer the first four research questions. The largest and smallest helpful behavior and obstacle items were identified in terms of their sizes. Also, the most and least frequently occurring helpful behavior and obstacle items were identified in term of their frequencies. Both perceived intensity scores and perceived severity scores were calculated and ranked from highest to lowest. Significant differences in nurses' perceptions in regard to nurses' characteristics were presented. The next chapter I am going to present detailed discussion of the results within existing literature and theoretical framework.

CHAPTER 5

DISCUSSION

The previous chapter presented the main results of the study. This chapter presents a discussion and clarification of the main study results which will include: interpretation of the findings, implications for nursing, limitation of the study, recommendations for further research, and conclusion.

Interpretation of the Findings

A total of 324 ICU-RNs completed the questionnaire. This sample represents about 35% of the total population. Male nurses consist about 59% of the sample, while female nurses consist the remaining 41%. In Jordan, the overall male nurses working in the health sector reached 70%, while female nurses consists about 30% (Al-Nsour, 2009). This variation could be due to the nature of ICU work that need recurrent exposure of the patients, which necessitate the presence of enough gender equivalent nurses, to be in line with Jordanian culture and Islamic religion. The percentages of Jordanian ICU-RNs' gender differs from those in other society. In the study of Beckstrand and Kirchhoff (2005) conducted in the United States, male nurses constitute about 6.6% of the sample, while female nurses were about 92.4%. This variation could be due to the reserved nature of the Jordanian culture that preferred females to work during the day more than nights which is not compatible with the nature of nursing work (especially if they are married). Jordanian policy makers and stakeholders are implementing plans to reverse the percentage of nurses' gender to satisfy the market needs that reach 70% for female nurses and 30% of male nurses (Al-Nsour, 2009). About 97.5% of the ICU-RNs were having bachelor degree in

nursing while only 2.5% were having master degree in nursing. Most nurses who have master degree in nursing usually seek an educational job in hospitals or universities, perhaps because this is socially more convenient and financially more beneficial. In the study of Beckstrand and Kirchhoff (2005), about 0.8% of participants were having doctoral degree, 14.1% having master degree, and 51.7% having bachelor's degree. While in the study of Gross (2006), only 4% (one nurse) of participants was having master degree in unspecified area, and none of the participants were having master degree in nursing. Diploma degree was completed by 9% of the nurses (two nurses), and 48% of nurses were completed their bachelor's degree in nursing.

Nurses in this study provided care for a number of EOL patients similar to that in Crump, et al. (2010) study, but fewer than Beckstrand and Kirchhoff (2005), and Gross (2006). Only 31.1 % of nurses provided EOL care to more than 30 patients, compared to 68.5% in the study of Beckstrand and Kirchhoff and 54% in the study of Gross. In Jordan, the concept of EOL care is still growing and maybe nurses are still unaware about which patients can be classified as EOL patient. Comprehensive and clear EOL care guidelines coupled with appropriate educational programs may help in improving nurses' preparedness for EOL care.

The majority of respondents were working in the middle region that contains many of the major cities of Jordan, including its capital (Amman), followed by the north and south regions respectively. This could be due to the distributions of Jordanian population in which the majority live in the middle region (62.5%) followed by north region (28.2%) and south region (9.3%) (DOS, 2004b). Also, about 65% of hospitals located in the middle region, 23% in the north region, and 12% in the south region (MOH, 2007, p13).

Jordanian ICU-RNs participated in the study were having an average of 4 years of nursing experience compared to 15 years in the study of Crump, et al. (2010), and 19 years in the study of Beckstrand and Kirchhoff (2005). Most experienced nurses in Jordan are seeking job opportunities in the Gulf region and worldwide, for more financial income (Al-Nsour, 2009). In Jordan, salaries are not meeting the daily requirements of professionals and their families. Insufficient salaries would lead to nurses' dissatisfaction and turnover. Nurses' job satisfaction was found to correlate significantly and positively with nurses' retention (Hayajneh, et al., 2009). So, Jordanian nurses migration (after gaining experience) to other countries will be reflected on the characteristics of nurses inside Jordan. For example, our study revealed that the mean age of ICU-RN in this study was 26.5 years, with average of only 4 years of nursing experience, which indicate high turnover state. The average turnover rate among registered nurses in Jordanian hospitals is 36.6%, which is considered high. Several factors may contribute to the high turnover rates among Jordanian nurses like high demand for nursing workforce by regional and international hospitals and health systems, gap in salaries and benefits between different hospitals, lack of recognition and low professional status, job dissatisfaction and in adequate opportunity for professional development, and excessive stress (Hayajneh, et al., 2009).

Research question 1.

For help size data, Cronbach's alpha was 0.91 which indicates that the scale scores are reasonably reliable for respondents, the questionnaire was suitable to Jordanian culture, and nurses share many common concerns. This was slightly higher than that for help size items in Beckstrand and Kirchhoff (2005) and Gross (2006) studies, which was 0.86.

The highest rated help size item was "having family members accept that the patient is dying”. This item was ranked as the second in the study of Beckstrand and Kirchhoff (2005), and Crump, et al. (2010). Family acceptance of patient’s death is usually facilitated when health care providers “creating heaven for safe passage”. This major theme was emerged in the study of Thompson, et al. (2006), which contained an important sub-theme named “facilitating and maintaining a lane change” that focus on the recognition of the families that the death is near and to shift their thinking from curative medical treatment toward comfort care. Changing lanes is usually facilitated when the patients and their families have clear understanding of the disease process and its outcomes, and when they are active participants in the decision making process. This can be obviously seen in our respondents rating of “family members not understanding what life-saving measures really mean” as the most frequently occurring obstacle. Nurses are usually satisfied when they help families in moving toward acceptance of patient’s situation and probable death, and to take decisions that had to be made (Popejoy, et al, 2009). Six of the top ten help size items were also perceived to be from the top 10 items in previous studies (Beckstrand and Kirchhoff, 2005; Crump, et al., 2010). Similar to the study of Gross (2006) most of these items were related to assuring a dignified death process for the patients and their families such as "providing a peaceful, dignified bedside scene for family members once the patient has died", "having enough time to prepare the family for the expected death of the patient", "allowing family members adequate time to be alone with the patient after he or she has died", and "a unit designed so that the family has a place to go to grieve in private". The remaining size items perceived to be from the top 10 helps were sharing a common theme. Those items are helpful to nurses because when they occur, the workload burden on nurses will be decreased during the stressful period of patient's death. This theme can be obviously

seen in items like "after the patient’s death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit", "having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient", and "letting the social worker or religious leader take primary care of the grieving family". The least helpful behavior seen by respondents was "having un-licensed personnel available to help care for dying patients". This finding was consistent with previous studies (Beckstrand and Kirchhoff, 2005; Crump et al., 2010) perhaps because nurses share the view that un-licensed personnel are incapable to care for the dying patients and their families.

Research question 2.

The internal consistency estimate of reliability was 0.91 for the help frequency data. Cronbach's alpha for the 24 items was higher than those in previous studies (Beckstrand & Kirchhoff, 2005; Gross, 2006). The scores of help frequency items in this study were remarkably lower than those of Beckstrand and Kirchhoff and Crump et al. (2010) studies. This indicates insufficient supportive behaviors for nurses in their delivery of EOL care. Six of the highest top 10 help frequency items were shared with the study of Beckstrand and Kirchhoff (2005), and seven items were shared with the study of Crump, et al. (2010). In depth analysis of the most frequently occurring help items reveals that they share a common theme. Most of the frequently used help items were depend on nurses primarily and do not need the presence of facility resources or other professionals (see item 2, 3, 4, 5, 6, & 8 in table 4). Interestingly, 4 of the top 10 help size items were rated to be a medium or least frequently occurring (see item 1, 3, 4, & 6 in table 3). That means nurses perceive the importance of certain help items but it is not available for them. For example

"providing a peaceful, dignified bedside scene for family members once the patient has died" and "allowing family members adequate time to be alone with the patient after he or she has died" are perceived among the top 10 size items, while they ranked 14th and 20th (respectively) based on their frequency of occurrence. This could be due to the limited areas of the already established ICU's that are difficult (if not possible) to change their construction. Also, the highest rated help size item "having family members accept that the patient is dying" was ranked 15th based on the frequency of occurrence. Even this help can be considered a large help, families not usually accepting that their patient is dying. This could be due to the strong and intimate bonds between family members, and their effort to use all available resources to help each other when they are in need for that.

Jordanian ICU-RNs perceive the importance of letting the social worker or religious leader take primary care of the grieving family, but only few Jordanian hospitals have social worker. Moreover, religious leaders are only available when requested or brought by the family. Religious leaders can play an important role in easing the dying process for the grieving families. Religious leaders can support patients and their families at EOL to satisfy their spiritual needs constructs. Those constructs may include love and belonging, holiness, positivity and hope, meaning and purpose, morality and ethics, appreciation of beauty, resolution and death, and control (Abbas & Panjwani , 2008).

It has been noticed in the study of Daaleman et al. (2008) that patients who receive spiritual support from facility staff rate care higher than those who did not, with no differences based on the presence of other sources of support. Spiritual care assessment for dying patients is a significant part of nursing practice. It has been found that most nurses

strongly agree that nursing responsibilities include addressing spirituality and not leaving the discussion to the hospital chaplain (Murray, 2010).

Similarly, social workers are uniquely equipped by education and training to work with individuals and their families. Social workers have a major role in guiding patients and their families in care planning. Their role in EOL practice can extend to be a counselor, context interpreter, advocate, and a team member who help in the identification and communication of physical pain, symptoms, and suffering (Beth, 2005).

Help intensity.

Multiplying help size means with help frequency means revealed help intensity scores, which were ranked in descending order. The range of perceived intensity scores for help items was from 6.29 to 9.63. This narrow range differs in magnitude from the range of Beckstrand (2001) study which was from 2.62 to 10.97. On the other hand, seven of the top 10 perceived help intensity scores were common between both studies. For example, "allowing family members adequate time to be alone with the patient after he or she has died" was ranked the second in our study and it was ranked the first in the study of Beckstrand (2001).

Even the perceived intensity score alone does not represent accurate reflection of how helpful the nurse perceived a support to be, however it will help in identifying which item is perceived to be more helpful for nurses and available for them at the same time. For example, "after the patient’s death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit" is perceived as the most helpful item and readily available for nurses while providing EOL care. Jordanian

ICU-RNs perceive the help of nurses do something that need to get done as a large social support behavior than nurses working in other wards (Mrayyan, 2009). So nurses may perceive the item “after the patient’s death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit” as a social support behavior in this stressful situation. High job stressors and low social support behaviors were evidenced in Jordanian ICU’s. Nurses’ job stressors could be due to workload, conflict with physicians, uncertainty concerning treatment, inadequate preparation, lack of support, and issues related to death and dying (Mrayyan, 2009). Death and dying seem to contribute to high burnout levels, especially for nurses who are in the front care-line of patients and families. Communication with families at those moments contribute to more stress for nurses (Pereira, Fonseca, & Carvalho, 2011), especially if the families are not accepting patient death. Caring for dying patients and their families is thought to be most stressful and painful to the nurses who must constantly attend for patients care needs (Beckstrand and Kirchhoff, 2005; McMillen, 2008; Ranse et al, 2010). Many nurses agree or strongly agree that caring for patients who are dying is depressing (Zapka et al, 2006), which may powerfully affect nurses turnover (Hamric & Blackhall, 2007). Nurses usually grieving for the loss of their patients and the emotional pain experienced by the family. Also, the difficulty of communication with highly stressed people in stressful circumstances affects all members of the health care team. This can be obviously seen in our respondents ranking of "having family members accept that the patient is dying" as the most helpful behavior in providing EOL care. This concept is magnified in the study due to the nature of Jordanian culture that characterized by strong family bonds and their denial of their patients death (Al-Hassan & Hweidi, 2004; Khalaf & Callister, 1997).

The least perceived intensity score was for the item " having un-licensed personnel available to help care for dying patients". This item was also ranked the least in Beckstrand (2001) study. Despite the difficulties nurses face in providing EOL care, they are less likely prefer to leave care for terminally ill patients to others. They definitely agree that caring for terminally ill patients is a rewarding part of their work (Vejlgaard & Addington-Hall, 2005). Noteworthy, un-licensed personnel are not allowed to work with ICU patients according to policies of Jordanian health institutions.

Research question 3.

The internal consistency reliability was 0.89 for the obstacle size data, which was similar to the one in the Beckstrand and Kirchhoff (2005) study and higher than the one in Gross (2006) study which was 0.86. Five of the top 10 obstacle size items were related directly to family issues. From them two items were also perceived to be a large obstacle, in the study of Beckstrand and Kirchhoff, Crump et al. (2010), and Gross. Those items were: "the nurse having to deal with angry family members", and "family members not understanding what life-saving measures really mean."

The reviewed literature perceived the item "the nurse having to deal with angry family members" as one of the top 10 obstacle size items (Beckstrand and Kirchhoff, 2005; Crump et al., 2010, Gross, 2006). In our study, this item ranked the first followed by the item " the nurse having to deal with confused family members while still providing care for the patient" which also perceived to be large in the study of Crump et al. Jordanian families of ICU patients are usually in need to receive information frequently, to feel that the hospital personnel care about their patient, to have the questions answered honestly, and to

know the patient progress and the expected outcome (Al-Hassan and Hweidi, 2004; Omari, 2009). So if the family feels that the nurse is not doing his/her role properly or communicate with them improperly, levels of anger and confusion of the patient's family will rise. Recently many incidents of verbal and physical assaults against medical staff from families were noticed. In a study conducted by the directorate of control and internal audit in the Jordanian ministry of health, it has been recorded 40 incidents of violence against medical staff in the governmental hospitals in 2009 compared with 30 incidents in 2008 (Sawalhah, 2009). This issue raised public and professional concerns to the rationale behind such phenomenon and call on the needs to investigate thoroughly.

In our study, Jordanian nurses perceived unit visiting hours that are too liberal as a large obstacle, while it was perceived as a small obstacle in the study of Beckstrand and Kirchhoff (2005) which ranked 28th, Crump et al. (2010) which ranked 27th , and Gross (2006) which ranked 20th, while it was ranked as the third largest obstacle size item in this study. This could be due to the workload of ICU-RNs in Jordan and the improper design of the ICUs which do not allow the peaceful presence of family members beside the patient. Also it has to be kept in mind that about 41.7% of our respondents are employed in private hospitals, which usually have minimal restrictions on the visiting hours and number of visitors. Visitors can limit nurses' ability to provide comprehensive care for the patient, and may take many of nurse's time which must be utilized in patient care. Parallel to that, respondents of this study perceived that "unit visiting hours that are too restrictive" as the smallest obstacle they face in providing EOL care for patients. In support of this view, data revealed that nurses working in the middle region (that contains more of the private hospitals) perceived the obstacle frequency item "unit visiting hours that are liberal" to

occur more frequently than what perceived by nurses who work in the north or south region (see table 14). Similarly, the obstacle size item "unit visiting hours that are too restrictive" was rated higher by nurses who work in the governmental hospitals than nurses working in the private or university hospitals (see table 13). Also, the nature of families differs between Jordan and other countries where similar studies were conducted. In Jordan, the “extended family” construct is more prominent than western countries in which “nuclear family” is common. This magnifies the visiting problem by the increased numbers of family members attending the patient room which increase the overall visiting hours, especially if there were no visits restriction policies in the hospital.

Through analysis of the respondents' perception of obstacle size items in relation to help size items revealed many interesting harmonies between their top 10 items. For example, respondents perceived "poor design of units which do not allow for privacy of dying patients or grieving family members" as a large obstacle. At the same time, they perceive "providing a peaceful, dignified bedside scene for family members once the patient has died" as a large help. Table 15 illustrates the compatibility between some of the top 10 help and obstacle size items.

Table 15: Some of the top 10 obstacle size items and their related top 10 help size items

Obstacle item	Related Help item
The nurse having to deal with angry family members.	Having family members accept that the patient is dying.
The nurse having to deal with confused family members while still providing care for the patient.	
Families not accepting what the physician is telling them about the patient’s poor	

prognosis.	
Poor design of units which do not allow for privacy of dying patients or grieving family members.	Providing a peaceful, dignified bedside scene for family members once the patient has died.
Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	Having enough time to prepare the family for the expected death of the patient.
Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	Having agreements between physicians involved in the patient's care about how the direction of care should go.
Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	Having one family member be the designated contact person for all other family members regarding patient information.

Research question 4.

Cronbach's alpha for the obstacle frequency data in this study was 0.88 for the 29 obstacle items, close to its counterpart alpha in Beckstrand and Kirchhoff (2005) and Gross (2006) studies which was (0.89 and 0.86) respectively. Three of the top 10 obstacle frequency items were shared between this study and the study of Beckstrand and Kirchhoff and Crump, et al. (2010). Those items were concerned with family issues like "family members not understanding what life-saving measures really mean", " family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information", and "not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life". Interestingly respondents in our study perceive that the most frequently occurring obstacles in providing EOL care to be related to family issues, which can be

obviously seen in their ranking of the first six obstacle frequency items (see table 7). Similarly, Nelson (2006), Beckstrand, et al (2008), and Beckstrand, et al (2009) found that the majority of obstacles facing nurses in their delivery of EOL care are usually related to family issues.

Results of this study revealed that the most frequently occurring obstacle item was "family members not understanding what life-saving measures really mean, i.e., that multiple needle sticks cause pain and bruising, that an endotracheal tube won't allow the patient to talk, or that ribs may be broken during chest compressions". This perception of Jordanian ICU-RNs was close to that obtained from ICU-RNs in the united states, who ranked this item between the top three frequently occurring obstacle (Beckstrand and Kirchhoff, 2005; Crump, et al. 2010). Similarly, Lloyd-williams, et al. (2009) found that "communication about death" is an important issue for the relatives of EOL patients. Relatives are usually do not understand several issues when their patients are dying. Health care providers should explain what is happening to the family by answering questions and providing information (Ranse, et al, 2010). Realistic information might help the families in making sound decisions as what to do next (al-Hassan and Heweidi, 2004). While unrealistic expectations from family are considered a significant barrier (Wang, et al, 2004). So, nurses role in educating and preparing families for patient's last moment can help in decreasing the barriers that face nurses in their delivery of EOL care.

Respondents in this study perceived "employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment" as the least frequently occurring obstacle, which was differently perceived to be frequently or moderately occurring obstacle by ICU-RNs in the United States (Beckstrand

and Kirchhoff, 2005; Crump, et al., 2010), In Jordan, advanced directives does not face nurses frequently as it is relatively recent concept and there is no policy or regulations addressing its legitimacy. Similarly, do not resuscitate orders still written cautiously with great confusion about its legitimacy and implementation. It is anticipated, that proper and comprehensive EOL care guidelines would help in systematize such issues and perhaps regulate its implementation.

The perceived severity score in this study were close to the result of Beckstrand (2001) study, in which 7 of the top 10 highest perceived severity scores items were common. Those items were 1, 2, 3, 5, 6, 8, and 10 in table 8. Also both studies perceived "unit visiting hours that are too restrictive" as one of the lowest perceived severity score items.

Research questions 5 and 6.

Secondary to our main purpose, we examined the differences between respondents' rating of the size and frequency of help and obstacle items and their characteristics. For the "years of ICU experience"; respondents were divided into two groups based on their means. Mann-Whitny U test was used to find the significant differences in responses between less experiences group and more experienced group. The same scenario was applied to the age variable. For comparing the responses of ICU-RNs based on the number of ICU patients received immediate EOL care, type of facility (healthy sector), and regional cluster; Kruskal Wallis test was performed because our dependent variables are ordinal, and we have more than two groups for the categorical variables (Newton and Rudestam, 1999; Warner, 2008).

The results revealed that the obstacle size item "continuing to provide advanced treatments to dying patients because of financial benefits to the hospital" was perceived by nurses with less ICU experience to be larger obstacle than what perceived by nurses with more ICU experience (see table 9). Similarly, the same item was perceived by nurses with age less than 26.5 years to be larger obstacle than nurses older than 26.5 years. Lack of enough experience especially with dying patients may affect younger nurses' perception and impact their level of stress, which may lead to higher obstacle scores. Years of experience is an important factor that significantly and positively correlates with nurses attitudes toward elderly patients (Hweidi & Al-Hassan, 2005). Also, less clinical experience with dying patients correlates with higher levels of discomfort for nurses (Weigel et al, 2007). More work experience enable nurses to know how to handle presented obstacles in the best way. Experience with dying patients helps the nurse to be able to discuss EOL care issues with patients, families, and other healthcare providers which provide a comprehensive picture of the situation that help in better understanding of the caring process (Tyree, et al, 2005).

The obstacle frequency item "pressure to limit family grieving after the patient’s death to accommodate a new admit to that room" was perceived by more experienced nurses to occur more frequently than what was perceived by the less experienced nurses. More experienced nurses are usually responsible for the organization of patient flow - in and out of the unit. They are responsible about patient transfers, especially if they are in charge. So, experienced nurses are more likely to limit family grieving after the patient's death than less experienced nurses to accommodate a new admit to the room. Similarly, the findings indicate that nurses who provide care for more than 30 EOL patients, perceived

this obstacle frequency item to occur more frequently than perceived by nurses who cared for 10 EOL patients or less (see table 12).

For supporting the opinion that more experienced nurses are responsible for the unit leadership which puts them in the first line of defense against EOL obstacles; it can be obviously seen that nurses who provided care for more than 30 EOL patients (more EOL experience) perceived many of the obstacle size and obstacle frequency items higher than what perceived by nurses who provided care for 10 EOL patients or less. More experience nurses are positioned to deal with angry family members, to be called by patients' family and friends to get an update on the patients' conditions, to limit family grieving after the patient's death to accommodate a new admit to the room, and to be aware of family members not understanding what life-saving measures mean (see table 12). Therefore, it seems that with more ICU experience nurses come in terms with the many demanding professional role they are expected to perform.

The help size item "Letting the social worker or religious leader take primary care of the grieving family" was perceived by older nurses as larger help than what perceived by younger nurses (see table 10). It has been found that older nurses exhibit more positive attitudes toward caring for dying patients and they are more likely to avoid talking about death and dying than younger nurses (Lange et al, 2008). So, older nurses view the presence of social worker or religious leader to take the primary care of the grieving family as a large help. Similarly, our findings indicate that nurses who provided EOL care for more than 30 patients perceived this item to be a larger help in size than what perceived by nurses who cared for 10 or less EOL patients (see table 12). This further indicates nurses' awareness about the importance of supporting family members of the EOL patients.

The peaceful end of life theory (Ruland & Moore, 1998) was used as a theoretical background of the study. Its outcome indicators were explored and compared to our findings to assess its suitability for Jordanian culture. Based on our results of the highly rated help behavior and obstacle items, one outcome criterion and several process criteria were suggested to the conceptual model. The outcome criterion “collaboration between health care providers” was added. Our findings indicated that many of the obstacles facing nurses in their delivery of EOL care to patients were due to the lack or insufficient collaboration between health care providers. The added process criteria related to this concept were: consulting and facilitating social workers to care for the grieving family, facilitating the delegation of some activities to other nurses like paperwork and preparing dead body, more involvement of experienced nurses in dealing with angry family members, and more involvement of nurses in the decision making process. For the already existed outcome criteria, several process criteria were added. Figure 3 illustrate the model with the newly suggested criteria.

Peaceful End of Life

Not being in pain
- Monitoring and administering pain relief
- Applying pharmacological and non pharmacological interventions
- *Discussing with physicians treatments that cause pain and suffering to patients

Experience of comfort
- Preventing, monitoring, and relieving physical discomfort
- Facilitating rest, relaxation and contentment
- Preventing complication
- *Expending enough time providing quality EOL care and preparing the family for patient death
- *Assigning one contact family member to be responsible about acquiring and disseminating patient's information

Experience of dignity / respect
- Including patient and significant others in decision making
- Treating patient with dignity, empathy and respect
- Being attentive to patient's expressed needs, wishes and preferences
- *Assigning private place for the family to grieve in private
- *Providing dignified bed side scene for the family after patient's death

Being at peace
- Providing emotional support
- Monitoring and meeting patient's needs for anti-anxiety medications
- Inspiring trust
- Providing patient/significant others with guidance in practical issues
- Providing physical assistance of another caring person, if desired
- *Being realistic with families about patient's status
- *Providing patients/significant others with information about usable term like life saving measures
- *Facilitate patient-family-nurse-physician communication process
- *Keep family updated about patient's condition

Closeness to significant others/persons who care
- Facilitating participation of significant others in patient care
- Attending to significant others grief, worries and questions
- Facilitating opportunities for family closeness
- *Teaching the families how to act around the patient scene
- *Facilitating the presence of family during the dying process
- *Allowing family adequate time to be alone after the patient death

*Collaboration between health care providers
- *Consulting and facilitating social workers to care for the grieving family
- *Facilitating the delegation of some activities to other nurses like paperwork and preparing dead body
- *More involvement of experienced nurses in dealing with angry family members
- *More involvement of nurses in the decision making process



Figure 3. Suggested Concepts of the Peaceful End of Life Theory.

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Strengths and Limitations of the Study

This study is the first in Jordan to report ICU nurses' perception of helpful behaviors and obstacles facing nurses in providing EOL care. Respondents were randomly selected from all Jordanian regions and health sectors (except military) which would minimize systematic bias and strengthen the study's internal and external validity.

Permission was not granted from the Royal Medical Services. Since military nurses compose a large sector of Jordanian RNs, generalizability of the findings would be limited to the population from which the sample was selected. Moreover, using cross sectional design provide a snapshot data, therefore it doesn't address whether perceptions of Jordanian ICU-RNs of helpful behaviors or obstacles would change overtime or not. As with any questionnaire research, results should be cautiously interpreted as it is self reported data.

Implications and Recommendations

Implications and recommendations for nursing practice.

Nurses usually spend more time with EOL patients than any other health care provider. So they should be equipped with the knowledge and practices needed to provide efficient EOL care. This study can form a cornerstone for the development of a Jordanian EOL care guideline that is culturally and religiously sensitive. Patients and families should have clear understanding of the disease process and its outcomes. Also they should be active participants in the decision making process, which facilitate changing lanes toward more peaceful death.

The finding of this study can help in directing EOL care practices of nurses. Nurses should be aware about the obstacles they may face, and how to deal with them in the proper way. The study increases Jordanian nurses' awareness about helpful behaviors and obstacles of EOL care. Therefore Nurses should optimize utilization of available resources to institute helpful practices and minimize obstacle ones when providing EOL care. This would improve patients and family outcomes and contribute toward achieving peaceful EOL. In contribution to that, the researcher is planning to provide each ICU in the country with a concise report of the main findings of the study and to-the-point recommendations, to help nurses achieve high quality EOL care. The following are example of such recommendations that focuses on decreasing the size and frequency of the most highly rated obstacles.

Recommendations for decreasing the size and frequency of the highly rated obstacles include:

1- Assess patients and families' understanding of terms such as life saving measures in order to clarify those concepts for them which will improve their role in the caring and decision making processes.
2- Open channels of communications between patients, families, and health care team members, to bridge the gap between plans of care of health care providers and wishes of patients and their families.
3- Educate nurses and physicians about the importance of providing families' with clear information about the patient status, to decrease their stress and to avoid their anger in critical situations.

4- More inclusion of social workers in caring process of EOL patients. Social workers should spend enough time assessing family's needs and their expectations. They can play a major role in dealing with family concerns and melting the boundaries between families and health care providers.

5- After the admission of patients to the ICU, families must be oriented to the units' policies, rules, and regulations specially visiting hours and how to collaborate with ICU-RNs for optimal patient care.

6- Discuss with the family the preferable way of disseminating patient's information on a regular basis in order to diminish the number of incoming calls handled by nurses. Organizing family meetings frequently to discuss their concerns and assigning a designated contact person to be updated about patient's status, could be helpful in organizing the communication process between the families and health care providers.

Implications and recommendations for nursing education.

Nursing educators can play a central role in improving EOL care practices because they are the one who are responsible about planting the main seeds for nursing practice. Nursing educators should raise the awareness of nursing students on issues related to EOL care. They should communicate with the students in the class room and clinical settings on the significance of recognizing EOL care obstacles and how to utilize helpful behaviors in closing the gap between nurses and EOL patients and their families.

End of life care should be included in nursing curriculum. Few Jordanian universities start to teach palliative care as a separate course which includes some EOL

issues. Other universities include EOL care issues as a chapter in a major course like medical-surgical nursing or geriatric nursing. Either way, there should be a collaboration between all educational institutes to come with a consensus agreement on the best method to incorporate concepts of EOL care systematically into nursing curricula.

Implications and recommendations for nursing research.

The present study focuses on the helpful behaviors and obstacles facing ICU-RNs in their delivery of EOL care. Suggestions for future research may include:

1- Testing the effect of implementing educational program for ICU-RNs containing a comprehensive national EOL care guidelines.

2- Investigating the perception of families' wishes regarding EOL care. Our findings ensured the effect of families on the overall caring process.

3- Investigating the factors that influence family anger and find ways to prevent any kind of violence against health care team members.

4- Systematic study to specifically evaluate the outcome of EOL care from the consumers and provider viewpoints (family members and nurses)

Implications and recommendations for policy makers and nursing leaders.

1- The inclusion of EOL care principles in hospitals' orientation programs

2- Continuous staff development and training on the provision of EOL care to help nurses develop clinical competence in understanding and dealing with the patient's family utilizing appropriate communication skills that are culturally and religiously sensitive.

3- Design units to create an environment for a peaceful EOL, ensuring private and dignified bed side scene, and providing private room for family grieving and meetings within the ICU area.

4- Encourage the development of cultural competence that includes better understanding of patients and families' cultures.

5- The inclusion of communication barriers and spiritual care in documented nursing care plans to keep nurses aware about those concepts.

6- Develop and implement EOL care guidelines with active input from the nurses to facilitate the smooth delivery of quality EOL care.

7- Organize supporting plans following a death in which colleagues help the assigned nurse in paper work and in preparing the body.

Conclusion

End of life care is an important aspect of daily nursing activities in the ICU. Jordanian nurses –like many other nurses worldwide- are striving to sanctify their mission in nurturing by caring for the bodies and souls of others. They are the faithful guard for dying patients especially in the ICU. Nurses neither can stop death nor cure the dying however, they can help in making the EOL moments and dying process peaceful. Devoting all possible resources for nurses is crucial to facilitate the achievement of their mission. Our study uncovered many of the obstacles that usually face Jordanian nurses in their delivery of EOL care. Many helpful behaviors were also identified. It can be obviously seen that family issues and hospital environment are important factors that influence Jordanian nurses in their delivery of EOL care. Collaboration of health care team members is fundamental for successful delivery of quality EOL care. Their fruitful inputs can only be

tasty when blended successfully with good communication, team work, sensitivity and appreciation for the feelings and needs of the dying and their family.

تم بحمد الله

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APPENDICES

Appendix A: Cover Letter and Consent Form

Cover Letter

Dear Registered Nurse;

I am Khaldoun M. Hamdan, a PhD nursing student in the University of Jordan. I am conducting a study to explore the perceptions of Jordanian intensive care nurses for the obstacles and facilitative behaviors that face them in the delivery of end-of-life care.

Study title: Jordanian intensive care nurses' perceptions of End-of-Life care: Helpful behaviors and Obstacles.

End-of-life care is one of the emerging care modalities that focus on the patients with non curative diseases (terminal illnesses) who are not responsive to medical treatment. In Jordan, the need to establish guidelines and policies that regulate practices and prevent conflicts that had frequently been faced with patients, their families and other health care providers. So we hope that this study will help us in establishing national database, which nurses can refer to when they take decisions

Dear Nurse, you were randomly selected to be one of the nurses who are being asked to participate in this national survey. Your participation will help all nurses in Jordan and worldwide to determine the real obstacles that prevent nurses from delivering end-of-life care. Also it will help in identifying facilitative behaviors essentials for this care.

Dear nurse, we need your help to assist us in understanding nurses perceptions of end-of-life care and thus improving the quality of our nursing practice. Please, answer all the questions, put it in the provided envelop and return it to your head nurse after being sealed. All information will be kept strictly confidential, and only the researcher will be allowed to look at the questionnaires. No need to write your name or any sign reflect your participation. You have the right to withdraw from the study anytime you like without any responsibility and without giving any justification. If you have any question about the study or its results please feel free to contact me.

Dear Nurse, your participation is highly appreciated

Sincerely,

Khaldoun M Hamdan. RN, PhD(c)

Mobile Phone: 0788298518

E-mail: khaldon_hamdan@hotmail.com

عزيزي الممرض،

انا الطالب خلدون حمدان، طالب دكتوراة في الجامعة الاردنية. ارغب في اجراء دراسة لمعرفة مفهوم ممرضي العناية المركزة في الاردن حول العوامل المساعدة و العقبات التي تواجههم في تقديم العناية للمرضى في نهاية حياتهم.

عنوان الدراسة: مفهوم ممرضي العناية المركزة الاردنيين فيما يتعلق بتقديم العناية للمرضى في نهاية حياتهم: العوامل المساعدة و العقبات.

تعتبر العناية بالمرضى في تهاية حياتهم احد وسائل العناية التي تهتم بالمرضى الذين لا يرجى شفاؤهم، واللذين لا يستجيبون للعناية الطبية. في الاردن نحن بحاجة لاستحداث مجموعة من القواعد و السياسات التي تنظم عملنا و تحد من الخلافات و تباين وجهات النظرالتي نواجهها مع المرضى و ذويهم و افراد الطاقم الطبي. لذا نأمل أن تقوم هذه الدراسة بتوفير قاعدة بيانات تساعدنا في اتخاذ قراراتنا.

عزيزي الممرض، لقد تم اختيارك بشكل عشوائي لتكون احد الممرضين المدعوين للمشاركة بالدراسة. مشاركتك ستساعد الممرضين في تحديد العقبات التي تواجه الممرضين في تقديم العناية للمرضى في نهاية حياتهم. كم انها ستساعد في تحديد العوامل التي تساعد في تقديم تلك العناية.

عزيزي الممرض، نحن بحاجة الى مساعدتك لكي نتمكن من استيعاب مستوى ادراك الممرضين فيما يتعلق بالعناية بالمرضى في نهاية حياتهم، و بالتالي تحسين نوعية الممارسات التمريضية. لذا نرجو منك الاجابة على جميع الاسئلة و وضعها في المغلف المرفق و من ثم اغلقه باحكام. ان مشاركتك في الدراسة اختيارية و جميع المعلومات سيتم الحفاظ على سريتها و لن يتم الاطلاع عليها الا من قبل الباحث نفسه. لا داعي لكتابة اسمك او اي علامة تدل على مشاركتك، و لك كامل الحق بالانسحاب من الدراسة متى تشاء.

واذا كان لديك اية اسئلة أو استفسارات فلا تتردد بالاتصال

عزيزي الممرض، لك جزيل الشكر على مشاركتك

خلدون حمدان

هاتف: 0788298518

بريد الكتروني: khaldon_hamdan@hotmail.com

Consent Form

Study Title: Jordanian intensive care nurses' perceptions of End-of-Life care: Helpful behaviors and Obstacles.

Main researcher: Khaldoun Hamdan - Nursing PhD student

Jordan University- Faculty of Nursing

Phone: 0788298518

E-mail: khaldon_hamdan@hotmail.com

Main supervisor: Dr Jafar Alasad

E-mail: jalasad@hotmail.com

Study Purpose:

This study will identify the real obstacles that prevent nurses from delivering end-of-life care. Also it will help in identifying facilitative behaviors essentials for this care. This will help in establishing guidelines and policies that regulate our practices and prevent conflicts that we frequently face with patients, their families and other health care providers. Understanding and organizing end of life care will help us (as nurses) in improving our quality of care, decreasing suffering and improving satisfaction of patients, families and nurses.

Targeted Population:

All Jordanian ICU nurses who cared for at least one end of life care patients, and who can read and write English.

Is your participation voluntary?

Dear Nurse, you have the right to participate or refuse participation in the study, and also you have the right to withdraw from the study at any time you like without providing any justification or having any responsibility.

Are your data confidential?

All your provided information will be highly confidential, as the research team only will be allowed to access the data. You don’t have to write your name or any sign that help in your identification, also the provided envelop will be opened by the researcher himself and be sure that data will be used for studying purposes only.

All the previous information are clearly understood and I agree to participate in this study

Participant signature :……………………….

Date :……………………….

نموذج موافقة على المشاركة في دراسة

عنوان الدراسة: مفهوم ممرضي العناية المركزة الاردنيين فيما يتعلق بتقديم العناية للمرضى في نهاية حياتهم: العوامل المساعدة و العقبات.

الباحث الرئيسي: خلدون حمدان\طالب دكتوراة

كلية التمريض- الجامعة الاردنية

هاتف: 0788298518

بريد الكتروني: khaldon_hamdan@hotmail.com

المشرف الرئيسي : د. جعفر الاسعد

بريد الكتروني: jalasad@hotmail.com

هدف الدراسة:-

تهدف هذه الدراسة الى تحديد المعوقات التي تمنع ممرضي العناية المركزة من تقديم العناية للمرضى في نهاية حياتهم. كما ستساهم في تحديد العوامل المساعدة لتقديم العناية، مما يساعد في انشاء مجموعة من القواعد و السياسات التي من شأنها تنظيم الممارسات التمريضية، و الحد من الخلافات و تباين وجهات النظر التي نواجهها مع المرضى و ذويهم و افراد الطاقم الطبي. ادراكنا و تنظيمنا لعناية المرضى في نهاية حياتهم سيساهم في تطوير نوعية العناية و تحسين رضى المرضى.

المستهدفون من الدراسة:

جميع ممرضي العناية المركزة الاردنيين، الذين قدموا العناية لمريض واحد في نهاية حياته على الاقل، ولديهم القدرة على قراءة و كتابة اللغة الانجليزية

هل مشاركتك في الدراسة اختيارية؟

عزيزي الممرض، لك الحق بالموافقة أو الرفض على المشاركة بالدراسة، كما يحق لك الانسحاب من الدراسة في اي وقت من دون ابداء الاسباب او تحمل اي مسؤولية

هل المعلومات المستخدمة سرية؟

جميع المعلومات المعطاة من قبلك ستعامل بسرية تامة، و لن يسمح لاحد الوصول اليها باستثناء الباحث نفسه. لا داعي لكتابة اسمك او اي علامة تدل على مشاركتك، كما ان المغلف المرفق سيتم فتحه من قبل الباحث نفسه. كن واثقا بان المعلومات ستستخدم لغايات الدراسة فقط.

جميع المعلمات السابقة الذكر مفهومة بشكل واضح و انا موافق على المشاركة بالدراسة

توقيع المشارك:......................................

التاريخ:..

Appendix B: Approval Letter to Use the Questionnaire

RE: hi
From: **Renea Beckstrand** (Renea_Beckstrand@byu.edu)
Sent: Monday, January 18, 2010 5:23:38 PM
To: khaldon hamdan (khaldon_hamdan@hotmail.com)
You have permission to change the tool to reflect your sample.

Renea L. Beckstrand

From: khaldon hamdan [mailto:khaldon_hamdan@hotmail.com]
Sent: Monday, January 18, 2010 2:04 AM
To: Renea Beckstrand
Subject: hi

Dear Dr Renea ,,
i would like to take the permission to use your tool "**NATIONAL SURVEY OF CRITICAL CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE"** in my study, and to make minor changes on the tool (if necessary) to suite my sample

thanks for your cooperation

Khaldoun Hamdan

Appendix C: **National Survey of Critical Care Nurses' Perceptions of End-of-Life Care**

Code___________

NATIONAL SURVEY OF CRITICAL CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE

The end of life is currently being recognized as an important life phase. Critical care nurses are frequently responsible for care of patients who are at the end of life and dying. Care dilemmas arise for nurses as dying patients are placed in an environment created to support and sustain life.

The following items pertain to your perceptions of possible **OBSTACLES** to providing end-of-life care to dying patients and their families. As you read each item, please mark the ***circle*** that most closely characterizes how ***large*** **an obstacle** you have found each item to be, then mark the **box** for how **frequently** you have experienced the obstacle as you have cared for dying patients.

0 = Not an Obstacle, **1** = Extremely Small, **2** = Small Obstacle, **3** = Medium Obstacle, **4** = Large Obstacle, **5** = Extremely Large

0 = Never Occurs, **1** = Almost Never Occurs, **2** = Sometimes Occur, **3** = Fairly Often Occurs, **4** = Very Often Occurs, **5** = Always Occurs

Item	Obstacle size	Frequency
1. Physicians who are overly optimistic to the family about the patient surviving.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
2. Families not accepting what the physician is telling them about the patient's poor prognosis.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
3. The nurse having to deal with confused family members while still providing care for the patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
4. Intra-family fighting about whether to continue or stop life support.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
5. The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
6. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

7. Poor design of units which do not allow for privacy of dying patients or grieving family members.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
8. Unit visiting hours that are too restrictive.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
9. The patient having pain that is difficult to control or alleviate.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
10. Dealing with the cultural differences that used by families in grieving for their dying family member.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
11. No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
12. Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
13. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
14. Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
15. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
16. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

17. Lack of nursing education and training regarding family grieving and quality end-of-life care.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
18. Physicians who won't allow the patient to die from the disease process.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
19. The unavailability of an ethics board or committee to review difficult patient cases.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
20. Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
21. Unit visiting hours that are too liberal.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
22. Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
23. The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
24. The nurse having to deal with angry family members.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
25. The family, for whatever reason, is not with the patient when he or she is dying.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

26. Physicians who are evasive and avoid having conversations with family members.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
27. Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
28. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
29. When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

30. Please describe any missing obstacles in detail. Indicate how large each obstacle is and how frequently it occurs.

a. ………………………………………………………………………………………… ………………….

b. ....

c. ………………………………………………………………………………………… ………………….

The following items pertain to your perceptions of possible **HELPS** to providing end-of-life care to dying patients and their families. As you read each item, please mark the ***circle*** that most closely characterizes how ***large a help*** you have found each item to be then mark the **box** for how **frequently** you have experienced the helpful behavior as you have cared for dying patients.

Help scale: **0** = Not a Help; **1** = Extremely Small; **2** = Small Help; **3** = Medium Help; **4** = Large Help; **5** = Extremely Large

Frequency scale: **0** = Never Occurs; **1** = Almost Never occur; **2** = Sometimes Occurs; **3** = Fairly Often Occurs; **4** = Very Often Occurs; **5** = Always Occurs

Item	Help	Frequency
31. Having one family member be the designated contact person for all other family members regarding patient information.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
32. Having enough time to prepare the family for the expected death of the patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
33. A unit designed so that the family has a place to go to grieve in private.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
34. Having agreements between physicians involved in the patient's care about how the direction of care should go.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
35. Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
36. The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
37. Having the family physically help with care for the dying patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
38. Talking with the patient about his or her feelings and thoughts about dying.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
39. Letting the social worker or religious leader take primary care of the grieving family.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

40. Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
41. Allowing families unlimited access to the dying patient even if it conflicts with nursing care some times.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
42. Providing a peaceful, dignified bedside scene for family members once the patient has died.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
43. Allowing family members adequate time to be alone with the patient after he or she has died.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
44. Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
45. Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
46. Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
47. Having a support person outside of the work setting who will listen to you after the death of your patient.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
48. Having family members thank you or in some other way show appreciation for your care of the patient who has died.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
49. Having an ethics committee member routinely attend unit rounds so they are involved from the beginning if an ethical situation with a patient arises later.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

50. Having family members accept that the patient is dying.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
51. After the patient's death, having support staff to collect all the necessary paper work for you which must be signed by the family before they leave the unit.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
52. Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
53. Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
54. Having un-licensed personnel available to help care for dying patients.	0 1 2 3 4 5 ± ± ± ± ± ±	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

55. Please describe any missing helpful behaviors in detail. Indicate how large the help is and how frequently it occurs.

A ………………………………………………………………………………………………..

B ………………………………………………………………………………………………...

C ……………………………………………………………………………………………

56. If you had the ability to change just one aspect of the end-of-life care given to dying ICU patients, what would it be?

………………………………………………………………………………………

Now please tell a little about yourself by filling in the appropriate boxes below.

57. How many years of nursing experience do you have as an **RN**? ………..

58. How many years of **ICU** experience do you have? ………….

59. What is your gender? □ Male□ Female

60. How old are you? ………..

61. What is your **highest completed** level of education?

□ Diploma degree, Nursing □ Associate degree, Nursing

□ Bachelors degree, Nursing □ Masters degree, Nursing

□ Doctoral degree

62. Over your nursing career, how many ICU patients have you, yourself given immediate end-of-life care to?

□ Less than 5 □ Between 11 and 20 □ More than 30
□ Between 5 and 10 □ Between 21 and 30 □ Other (specify)……..

63. In which **type of ICU** are you primarily employed?

□ General Intensive Care Unit (ICU) □ Medical ICU □ Neuro/Neurosurgical ICU
□ Coronary Care Unit (CCU) □ Surgical ICU □ Shock/Trauma Unit
□ Combined ICU/CCU □ Respiratory ICU □ Cardiovascular ICU
□ Other (Please specify) ……………

64. In which **type of facility** are you primarily employed?

□ Governmental Hospital □ Private Hospital
□ University Hospital □ Other

65. The **position** you hold at the facility is?

□ Direct care/Bedside/Staff Nurse □ Clinical Nurse Specialist
□ Charge Nurse/Staff Nurse □ Other (Please specify)

66. What is the number of beds in your unit? ………
67. How many **hours per week** do you usually work as an **RN**? ………

68. Do you currently have any other nursing certifications? If so, please list them below.

…………………………………………………………………………………….

69. Do you have any comments about end of life care in the ICU or about this study?

…………………………………………………………………………………….

…………………………………………………………………………………………….

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.
PLEASE RETURN THE QUESTIONNAIRE TODAY
TO YOUR HEAD-NURSE

KHALDOUN M. HAMDAN, RN, MSN, PhD (c)
Phone number: 0788 29 85 18
khaldon_hamdan@hotmail.com

Appendix D: Permission to Use "The Peaceful End of Life Theory"

SV: requesting permission

From: **Cornelia Ruland** (Cornelia.Ruland@rr-research.no)

Sent: Thursday, June 17, 2010 10:31:08 PM

To: khaldon hamdan (khaldon_hamdan@hotmail.com)

Dear Khaldoun Hamdan,

Please feel free to use the theory for your study. I would appreciate to be informed when you publish your results.

Good luck with your work!

Sincerely,

Cornelia Ruland

Fra: khaldon hamdan [mailto:khaldon_hamdan@hotmail.com]
Sendt: to 17.06.2010 14:56
Til: cornelia.ruland@dmi.columbia.edu; cornelia.ruland@rikshospitalet.no
Emne: requesting permission

Dear Dr Ruland,
am khaldoun hamdan, a nursing PhD candidate in the University of Jordan.
am conducting a study entitled " Jordanian Nurses' Perceptions of End-of-Life Care: Obstacles and Auxiliaries " i would like to use your theory of "the peaceful end of life" to enrich my study,
so i would like to take the permission to use the model.
thank you for your cooperation

Khaldoun Hamdan

Hotmail: Free, trusted and rich email service. Get it now.

Re: hi

From: **Shirley Moore** (smm8@case.edu)

Sent: Sunday, July 18, 2010 7:35:11 PM

To: khaldon hamdan (khaldon_hamdan@hotmail.com)

Yes. You have my permission as well. Good luck on your study.

Shirley

2010/7/18 khaldon hamdan <khaldon_hamdan@hotmail.com>

Dear Dr Moore,
am khaldoun hamdan, a nursing PhD candidate in the University of Jordan.
am conducting a study entitled " Jordanian Nurses' Perceptions of End-of-Life Care: Obstacles and Auxiliaries " i would like to use your theory of "the peaceful end of life" to enrich my study,
i took permission from Dr Ruland and i would like to take the permission to use the model from you as well.
thank you for your cooperation

Khaldoun Hamdan

Appendix E: Form Used in Pilot Testing

Pilot Testing

After completing the provided questionnaire, please answer the following questions, which may help in evaluating the questionnaire in terms of clarity, feasibility and appropriateness to the reader.

1- How long did it take to complete the questionnaire? …………………./.minutes

2- Were the instructions clear? ☐ Yes ☐ No

3- Was the language clear? ☐ Yes ☐ No

4- Were any questions unclear or ambiguous? ☐ Yes ☐ No

If yes, which one?...

5- Did you object to answering any questions? ☐ Yes ☐ No

If yes, which one?...

6- Was the layout clear and attractive? ☐ Yes ☐ No

7- Do you think that the questions were consistent with the study purpose?

☐ Yes ☐ No

8- Any other comments?

____

____

مفهوم ممرضي العناية المركزة الاردنيين فيما يتعلق بتقديم العناية للمرضى في نهاية حياتهم: العوامل المساعدة و العقبات

اعداد
خلدون محمد حمدان

المشرف
الدكتور جعفر الاسعد

المشرف المشارك
الدكتورة رينيه بيكستراند

ملخص

اهمية الدراسة

ان عدد المرضى المصابين بأمراض لا يرجى شفاؤها و الذين هم بحاجة الى العناية في نهاية الحياة ، في تزايد مستمر خصوصا في قسم العناية المركزة. كما يواجه الممرضين و الممرضات العديد من العقبات اثناء تقديمهم العناية للمرضى في نهاية حياتهم. في الاردن، ما زالت العناية بالمرضى في نهاية حياتهم في بدايتها، دون وجود مبادىء توجيهية واضحة. لذا، فإن تحديد العقبات و العوامل المساعدة التي تواجه الممرضين اثناء تقديمهم العناية للمرضى في نهاية حياتهم قد تساعد في تشكيل المعايير اللازمة لتقديم عناية تمريضية ذات جودة عالية.

الهدف

تهدف هذه الدراسة الى استطلاع مفهوم ممرضي العناية المركزة الاردنيين للعوامل المساعدة و العقبات التي تواجههم اثناء تقديم العناية للمرضى في نهاية حياتهم من حيث الحجم و التكرار.

منهجية البحث

تم استخدام الطريقة المقطعية في الدراسة حيث تم جمع العينة من خلال استخدام طريقة العينة العشوائية الطبقية، معتمدين على نسب الممرضين في الاقاليم (شمال و وسط و جنوب) بالاضافة الى نسبهم في القطاعات الصحية المختلفة (حكومي و خاص و تعليمي).

النتائج

ثلاثمائه و اربع و عشرون ممرض و ممرضة اكملوا الاستبيان. كان اكبر العوامل المساعدة حجما في تقديم العناية للمرضى في نهاية حياتهم ما يلي: "تقبل افراد العائلة لاحتضار المريض" و " قيام احد الزملاء بعد موت المريض بجمع الاوراق المطلوب توقيعها من الاهل قبل مغادرتهم للقسم" و " توفير جو مناسب و هادىء و جليل للاهل بجانب السرير في حالة وفاة المريض".كما كانت اكبر العقبات التي تواجه الممرضين ما يلي: " على الممرض التعامل مع افراد العائلة الغاضبين" و " على الممرض

التعامل مع اهل المريض المضطربين بينما يستمر بتقديم العناية للمريض" و " كثرة ساعات الزيارة المتاحة في القسم".

الخلاصة

ان العديد من العقبات الكبيرة (من وجهة نظر ممرضي العناية المركزة الاردنيين) كانت عائدة الى مسائل لها علاقة بعائلات المرضى و بيئة المستشفى. كما انه من الواضح أن التعاون بين افراد الطاقم الطبي المقدمين للعناية له دور كبير في نجاح ايصال العناية المناسبة للمرضى في نهاية حياتهم.